

**The constraints of the ordinary: 'Being with' patients
in a hospice in Scotland**

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DECLARATION

I declare that I have composed this thesis and that the work is my own.

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Abstract

The phenomenon 'being with', in relation to caring for patients who are close to death, is an important aspect underlying specialist palliative care. This study examines how 'being with' is constructed in day-to-day nursing practice in an inpatient hospice in Scotland.

This thesis begins with a formulation of 'being with' in facing death as part of Cicely Saunders' notion of a better way of caring for dying patients. The thesis proceeds to outline my methodological and analytical approach using principles of ethnomethodology developed by Harold Garfinkel and Charles Taylor's philosophy of interpretation. Four chapters then present the analysis of data, drawing predominantly on material gathered through observation.

In the beginning of this study, the nurses and nursing care assistants told me that 'being with' was part of their day-to-day care within the hospice. We seemed to share the same understanding of the phenomenon. However, I concluded during participant observation that 'being with' in facing death, as formulated by Saunders, was absent from the day-to-day care of patients in the hospice. By devising a methodology and approaches to analysis of data based on Garfinkel's and Taylor's work, I came to understand that the nurses' and nursing care assistants' perception of 'being with' was different from the way Saunders formulated 'being with'. I argue that the nurses' and nursing care assistants had constructed 'being with' when caring for patients who were close to death as providing comfort rather than dealing with the uncomfortable psychological and emotional effects of facing death. The consequence of this was that the patients were 'comforted' but they were not encouraged to face death in the way Saunders suggests, and as I had endeavoured to do in my own practice, thus leaving out an important part of specialist palliative care.

In the last chapters of the thesis I discuss my findings by revisiting Saunders' notion of 'being with' as a better way of caring for dying patients, and by exploring Heidegger's ideas of how human beings can face death. Through revisiting Saunders' notion of 'being with', I came to the view that there is a tension between the 'theory' and the 'practice' of 'being with' in relation to its practical outworking. It may be that Saunders has underestimated how difficult it is for nurses and nursing care assistants to 'be with' patients in facing death due to the physical demands of caring for dying patients and secondly to facing death per se. In this discussion I compare Saunders' discussion of the phenomenon of death with that of Heidegger. There are similarities between their understandings but I also found tension between their thinking. By exploring this I conclude that the nurses and nursing care assistants had constructed 'being with' in terms of providing comfort in order to manage both their own and their patients' feelings and thoughts about death and dying. On the basis of this study I offer some important insights into the tension between the hospice ideology of a 'good death' as provided by Saunders, and the day-to-day management of care of dying patients in this hospice.

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CHAPTER ONE

Introduction

True beginning includes strangeness, darkness, insecurity (Heidegger 1961)

Initiation of the Research

As a newly graduated nurse, in 1987, I was introduced to Cicely Saunders' hospice framework¹ of caring for dying patients. I joined a small group of nurses and doctors who were interested in developing this approach in caring for dying patients in Iceland and together we pioneered the palliative care² approach within the health care system there. As a result of our interest and effort, a specialist, palliative home care service, a hospital-based palliative care team and an in-patients hospice were established³. None of us in the group had formal training in palliative care. We taught each other and ourselves by reading what had been published on this subject, attending conferences and workshops abroad and then teaching other health care professionals in Iceland who were caring for dying people. I applied the knowledge I gained in my practice by doing clinical work and reflecting on it as well as teaching it to others. It was a continuing process of learning by practising and teaching palliative care. As a result, I became particularly interested in Saunders' philosophy of facing death and her belief that part of palliative care practice should involve 'being with' those facing death. My interest was two-sided. Firstly, from a personal viewpoint, I found Saunders' discussion of facing death rather than avoiding it fascinating in

¹ 'Hospice' is the word that Saunders herself used to describe her model of care for dying patients and their families. The use of the word 'hospice' has historical and religious roots that inspired Saunders to use it to describe her establishment (Saunders 1993, 1996a).

² The word 'palliative care' was first used by Balfour Mount, who worked with Saunders at St Christopher's hospice, to describe the approach that Saunders developed too caring for dying patients. He established palliative care unit in Canada (Clark 2002a, Saunders 1993). This is the word that has been used within the World Health Organisation to describe best practice of care for patients with a condition that is beyond cure (WHO 1990). In this thesis both 'palliative care' and 'hospice' will be used when referring to Saunders' work.

³ For a detailed account of the palliative care approach as developed by Saunders see Saunders and Sykes (1993).

relation to a philosophy of living. Secondly, from a professional viewpoint, in trying this approach I felt it produced positive responses from patients. I believed that the foundation that Saunders had developed through her practice and through her writings was appropriate. I became interested in exploring this approach from both a professional and a personal point of view.

For further explanation of how Saunders' approach had influenced me to engage with what the patient was experiencing when close to death rather than to avoid it I will give an example from my own practice.

A vignette: 'there is nothing to be done'

I went to see a patient in his home as part of my practice as a community nurse specialist in palliative care. This patient had advanced disease and was close to death. I had been asked to visit mainly to give support to the family who were looking after him and providing all the hands-on care. The main focus of the home visit was to talk to the family and give them support, advice and reassurance. I went into the house and talked to the family in the kitchen. After I had talked with them about their concerns, I reassured them that the care they were giving was appropriate. I asked if I could go and see the patient who was in bed upstairs. His wife and son looked at each other with surprise and said that it was not really necessary as they were doing everything for him and I would not need to do anything. I agreed with that but said that I would still like to see the patient. They nodded but were still a bit surprised. When I went into the patient's room it was dark and the curtains were closed. The patient was lying in his bed. I took a chair and sat by his bed. I introduced myself and told him who I was. I asked him how he was feeling. He told me that he was feeling all right but found it difficult to talk. He did not really have enough strength to talk. He also preferred to lie in the dark because he could not tolerate the light well. I decided to sit by his bed in silence for a while. Influenced by Saunders' approach, I believed that even though there was nothing that needed to be done for the patient and he preferred not to have conversation, he might benefit from me just 'being there'. However, I felt very insecure sitting there in the dark not saying anything. I remember thinking "What am I doing?" and "This feels odd." I don't remember how long I sat there. I suppose it seemed longer than it was. After what I thought was an appropriate length of time I stood up and told the patient I would visit the next day. I did this on a few occasions and the visit was always structured in the same way. I would start by

talking to the family and then go upstairs and sit with the patient in the dark room in silence.

Once, when I came for a visit, the patient was going into the hospital the next day for chemotherapy. It was very unlikely he would survive the treatment and come back home. I disagreed with the decision that had been made about continuing the chemotherapy despite the progress of the patient's disease. However, I had not been allowed to discuss the possible outcome of the treatment with the patient as his consultant was convinced this was the right thing to do, and the family and patient had agreed. I knew this would be the last time I would see the patient. As usual, I sat by his bed for a short period of time. When I stood up to go I reached out my hand and was just going to touch his duvet but the patient grabbed my hand and for a few seconds we held hands in a handshake. I felt, through that handshake, I got the answer that I had been looking for. My doubts disappeared and the activity of sitting in silence in the dark began to make some sense to me. I believe that the way the patient held my hand was a way of showing me his gratitude, since I was there with him even though there was nothing that I could do. I also thought that the patient knew, as well as I, that we would not see each other again. The handshake touched me in a way that encouraged me and minimised the emotional pain of the moment. I don't know if it encouraged him and minimised his emotional pain but, according to Saunders' theory, this was the right thing to do for a patient when nothing else could be done. We were two human beings who met in our humanity, just as Saunders described, and I believe such an approach could be helpful for patients who are facing death and as well as the health care professionals who care for them. It would have been emotionally less demanding to have avoided the patient than be challenged by the situation of sitting in the dark with someone who was close to death, especially someone I had not seen before, and feel the emotional pain that was associated with such a situation. I did not choose that option. Through this experience I began to believe that Saunders was right and decided to continue to use and explore her approach. Based on knowledge from Saunders' writings, I structured my practice of sitting in the dark with the patient even though there was nothing to do and, in the same way as Saunders, I believed it was helpful⁴.

Despite my confidence that this was important I was also left with the uncomfortable feeling of having done nothing. This motivated me to explore the concept of 'being with' within palliative nursing practice. This thesis is the fruit of what was sown in my practice many years ago when I sat in the dark beside a man who was dying.

⁴ Roy (1997) makes a case that palliative care is about staying with the person in their suffering even at times when nothing can be said to relieve the suffering.

The research question

Despite my own belief that I was doing something that mattered, the insecurity that 'being with' was connected with bothered me. I felt strongly that 'being with' wasn't doing nothing. What was it then? How could I describe this activity from a professional point of view? When discussing this with my colleagues they confirmed that we referred to this activity as 'doing nothing' when in fact we felt that it was doing something. It was so embedded in our practice that we did not have to explain it in order to be accountable to each other. We could go and see a patient and when asked what had been done for the patient we could say "nothing" and that was fully acceptable, not because 'doing nothing' was approved of but because everyone knew that 'doing nothing' actually involved 'being with' and was an important part of our practice as palliative care specialist nurses. It became clear that there was some specific meaning behind the term 'doing nothing' or just 'being with' that did not require explanation amongst us. However I found it problematic that while I experienced 'being with' as difficult to do emotionally and practically (as described in the above example) it was defined as 'doing nothing'. It was clear that 'doing nothing' had meaning that was not self-evident.

I considered whether 'doing nothing' was used because of the dominant medical model in health care that emphasised a cure-oriented approach. I became interested in trying to gain a more meaningful description of the phenomenon 'being with' than 'doing nothing'. I was concerned that, describing this activity as 'doing nothing' would both convey the low status of this work and devalue it.

The study answers the research question "How do nurses do 'being with' in an inpatient hospice alongside day-to-day practice?"⁵. Readers will notice, as they move through the thesis, that the original research question that emerged from my own

⁵ My own practice in relation to the phenomenon 'being with' is within the community as well as being a specialist consultant nurse within the hospital where I did not have the demands of caring for the patients I saw on a day-to-day basis. The fact that my study is in an inpatient hospice may be reflected in the findings. However usually there is no distinction made within palliative care between 'being with' in inpatient units or out in the community or as part of specialist palliative care service within hospitals. The Hospice inpatient setting is considered to provide specialist palliative care nursing.

practice developed as my understanding of 'being with' was affected by researching the phenomenon in a hospice unit. Instead of unfolding how 'being with' happens based on my original understanding it reflects my evolving understanding of the phenomenon as related to day-to-day practice in the hospice where I did my study, namely 'being with' as providing comfort. The focus of the study did not change nor did the research question. But, I came to answer it through discovering how it was understood by the nurses/nursing care assistants in the hospice where I did the study. Furthermore by holding my own prior understanding of the phenomenon I discovered why the nurses/nursing care assistants had constructed the phenomenon in the way they had. As a result of this a new understanding developed which is presented in this thesis.

Engaging the reader

The quote from Heidegger (1961) at the beginning of this chapter relates to my feelings when considering the meaning of 'being with' based on Saunders' notion that triggered this research, but it also represents my feelings when starting the data collection.

I had told the nurses and nursing care assistants in the field where I did my study that I wanted to research the 'being with' approach. I gave them examples from my own practice, one of which I have described above. They agreed and said that this was also an important part of their practice. However, as I began collecting data, I started to realise that their understanding of 'being with' was different from mine. During my observation of their practice this became evident, as I did not see them practise the approach of 'being with' that I was referring to. According to my understanding, the phenomenon 'being with' was missing from the care I saw being given but their opinion was that it wasn't. In this thesis I will show that 'being with' was taken for granted by them and was being practised and embedded in their practice. However, it was very different from the implementation of 'being with' in my own practice.

My concern at not seeing 'being with' in the hospice where I was doing my research only highlighted my own assumptions that 'being with', in the way that I understood it, is always practised in specialist palliative nursing practice. What I began to

understand was that 'being with' in facing death might be difficult to incorporate into day-to-day practice. My own understanding of the phenomenon 'being with', prior to doing this study, was in relation to how nurses in palliative care engage with patients on an emotional level regarding the fact that they are close to death. However, in doing this study my understanding of the phenomenon progressed. As I aimed towards an understanding of the way nurses/ncas in a hospice had constructed the phenomenon as part of their day-to-day practice as providing comfort rather than facing death, I started to understand the constraints of the ordinary work. I developed an understanding of how environmental and cultural issues affected the nurses/ncas' ability to do 'being with' in facing death. I also developed an understanding of the difficulties that facing death imposes on nurses/ncas working in a hospice. This understanding revealed to me a new perception of the practice of 'being with'. The way this thesis is written reflects my own journey of understanding. It reflects my own discovery throughout doing the study characterised by a shift in understanding of the phenomenon 'being with' in facing death.

One of my principal intentions in writing this thesis is to convey the understanding of the phenomenon 'being with' as perceived by nurses/ncas caring for dying patients on a day-to-day basis. This exposed the environmental and cultural barriers that inhibited 'being with' in facing death to be part of the nursing practice. In addition, I propose to reveal the ideological status of Saunders' philosophy in the light of my data. In presenting my findings I will offer the reader evidence related to the progress of my journey and invite the reader to travel with me as I develop my interpretation. Accordingly, the style of writing will reflect the progressive development of my understanding. This means that the same data is being used on different occasions to show different levels of understanding.

The structure of this thesis

Following this brief introduction to the topic of this thesis and how I came to study it, chapter two describes Cicely Saunders' approach of 'being with' in facing death. I will formulate my understanding of the concept based on her writings. I will also

draw on some nursing literature in order to discuss the concept as part of nursing practice. As the reader will notice, my understanding of the phenomenon 'being with' in facing death progressed throughout the study and what became relevant was to consider Heidegger's (1962) theory of how human beings can face death in order to explain what was going on. In chapter two I will also discuss 'being with' in relation to Heidegger's (1962) philosophy. I will then progress with using Heidegger's (1962) work as a theoretical underpinning of my analysis in chapter eight and nine.

Chapter three will discuss the methodology of this study. Ethnomethodology (Garfinkel 1967) was my key resource in the beginning of this study, when considering appropriate methodology for this research. It considerably shaped the way I collected data, but there were also aspects of it that I could not use and in this chapter these will be discussed. Hence, Taylor's (1985) philosophy of interpretation was critical for the analysis of data and in chapter three I will outline how his approach to interpretation was used in this research.

Chapters four, five, six and seven will provide a full account of my findings. In keeping with the progressive nature of the understanding I developed during the course of the study, I present the data chapters in a way that represents my own journey of understanding. Chapter four documents a typical shift at the hospice. It captures the ordinary day-to-day work of the nurses and nursing care assistants. It demonstrates their busyness, and the routinised way they organise care. Chapter five describes the effect of the nurses/ncas' work, namely, that because of the way care is organised, its emphasis is on comfort. Chapter six considers the nurses/ncas' ethos of care, an ethos that highlights giving comfort as a less emotionally demanding way of dealing with death and dying than facing death. It emerged out of this work that the issue of death and dying plays a major role with regard to the difference between the way the nurses and nursing care assistants constructed 'being with' as providing comfort and my own understanding of 'being with' in facing death. Therefore, how they dealt with death is given specific attention in chapter seven.

In chapter eight I will again revisit Saunders' notion of 'being with' in facing death and compare it with the findings of the study, that is, for the nurses and nursing care assistants, in the hospice where I did my research, 'being with' was providing

comfort. I will show that the way the nurses and the nursing care assistants in this study had constructed the care enabled them only to practice 'being with' by providing comfort, which excluded 'being with' in facing death within the day-to-day nursing care. However, these findings also challenged my own assumptions of the phenomenon 'being with' which was based on Saunders' writings. Hence in this chapter I revisit Saunders' writings in the light of my findings. It is suggested that 'being with' in facing death could be more difficult in practice than Saunders acknowledged when establishing her approach. Finally I will argue that Heidegger's (1962) theory of facing death helps us to understand why the nurses and nursing care assistants had constructed 'being with' as providing comfort rather than in facing death. By constructing 'being with' as comfort rather than in facing death, nurses/nursing care assistants managed to avoid the emotional demands facing death requires. In chapter nine I bring this thesis to its final conclusion. The key finding of this study is that facing death, that I argue is an important element of palliative nursing practice, was not part of the nursing care practice in the hospice where I did my study. The study also highlights that in order for the nurses and nursing care assistants to practise 'being with' in facing death they needed to shift their attitude to death from that of the dominant social view. Furthermore for nurses to do 'being with' in facing death requires supportive strategies to be embedded into the structure of day-to-day practice in a systematic way. This has important implications for managers and practitioners with regard to how day-to-day care is constructed in a hospice.

CHAPTER TWO

‘Being with’ in facing death

Introduction

The starting point of this research is based on my own assumptions and I had a question regarding the phenomenon ‘being with’ that was established through my own practice as a palliative care nurse. When I was involved in establishing the palliative care approach in Iceland, Cicely Saunders was our key source as she was the person who pioneered this approach in the UK. She did not define the concept ‘being with’ as such but the meaning of it was embedded in her practice, writings, and teaching and enormously influenced the way dying patients were cared for, with openness towards death and dying. This was a different approach towards caring for dying patients than was practised in the late 1950’s and early 1960’s as it was inclusive of emotions and thoughts in relation to death and dying. Saunders believed that health care professionals had a major role in facilitating this approach. Prior to this study I was aware of the meaning of ‘being with’ based on my reading of Saunders. I was inspired and influenced by her approach which was reflected in my practice as the example in chapter one shows.

This chapter takes the form of demonstrating ideologically Saunders’ work and her idea of ‘being with’ in facing death as a better way of caring for dying patients. I will formulate and make explicit my own understanding of ‘being with’ in facing death based on Saunders’ writings. I will show how the phenomenon ‘being with’ in facing death is explicitly related to an open awareness of death in Saunders’ writing. She advocates telling the truth and giving an opportunity to prepare for death and promote personal growth in the final stage of life. For Saunders this was a better way to die and health care professionals had a major part to play in order for this to happen.

Saunders is the key figure in relation to the establishment of palliative care.

[Her] life work led to the creation of St Christopher's hospice in London, the development of the international Hospice/Palliative Care movement, the birth of palliative care medicine" (Mount 2002 p. V).

I consider it fundamental for the reader to have an established notion of 'being with' as represented by Cicely Saunders' work since that was my own starting point in doing this thesis. As noted this reflects the ideological status of her work but what I discovered throughout doing this study was that it might be difficult to implement Saunders philosophy of 'being with' as facing death into day-to-day practice. As this thesis progresses I will show how my own understanding of Saunders work became more critical as I reflected on how it would be possible to implement her approach into everyday practice. As I will illustrate by reference to other writers, Saunders' belief of a better way of caring for dying patients formulated in this thesis as 'being with' in facing death is still the dominant understanding in palliative care. What will become evident to the reader is that the way 'being with' is understood theoretically in palliative care is quite different from its practical outworking in the hospice where I did my study. A critical account of Saunders' work is provided in chapter eight. In this chapter I will consider the ideology of the hospice movement in relation to 'being with' as facing death in the light of my data and Heidegger's theory of facing death.

Searching the literature

Within nursing literature 'being with' is demonstrated in the same ideological way as in Saunders' writings. I only became aware of this in doing this study. Prior to my fieldwork, I did an electronic search on the concept of 'presence' within nursing literature. However, in the way this study evolved it became less and less relevant to include these papers into the literature review. They only added to the ideological state of 'being with' as a phenomenon within palliative nursing practice rather than adding to the description of how the concept 'being with' actually happens in day-to-day practice. Some of the literature I found in the beginning of my work is included in the literature review to demonstrate the ideological status of 'being with/presence' in

nursing. However, in the way this thesis progresses, it became increasingly relevant to include nursing literature that would demonstrate the complexity of the phenomenon 'being with' as it actually happens in practice. In this respect manual search was a more important part of this study rather than an electronic one and continued to be an important part of the subsequent searches. This included the pursuit of references from other identified papers, browsing through nursing and palliative care literature on related topics and discovering papers by talking to colleagues.

In this thesis I do not differentiate between material read prior to, during or after data collection. The main argument of this thesis is focused around developing an understanding of why the nurses/ ncas in M Hospice did not do 'being with' in facing death. When doing my research it became evident that this would be the main argument of the thesis and this shaped what was considered as relevant literature and what was less relevant when writing this thesis. The literature review as it stands reflects this.

In formulating 'being with' in facing death as part of palliative care I draw on Saunders' writings (1959, 1965a, 1965b, 1969, 1981, 1983, 1984, 1986, 1990, 1993, 1996a 1996b). As noted, Saunders established a new speciality within the health care system, namely palliative care, and her publications reflect her thinking, teaching and knowledge base that this speciality is built upon. Clark (1998, 1999, 2002a, 2002b, 2006) has done extensive and valuable work in producing an immediate guide to Saunders' work. When reading Saunders' publications I searched for papers/books that would allow me to show how 'being with' in facing death was part of her movement. I included papers that addressed the issue of death and the emotional support that patients needed when close to dying. I excluded papers that addressed the physical aspects of caring for dying patients. I was also aware of the importance of capturing any differences that might be in earlier and subsequent writings. This was not the case; in fact Saunders reinforced her beliefs throughout her writings. By reading through her publications stated above I identified passages that presented Saunders' ideas in relation to 'being with'.

It became important to pay specific attention to the fact that in palliative care as established by Saunders, the phenomenon 'being with' is related to an open awareness

of death. Hence, became an important part of this study. What became relevant was to use Heidegger's (1962) ideas of death to understand what was happening in the palliative care field. His work is introduced in this chapter and discussed in greater depth later on in the thesis.

'Being with' and the nursing literature

When I explored the nursing literature for the phenomenon 'being with' at the beginning of this study, it became evident that it is discussed within nursing literature. The concepts of 'being with', 'being there' and 'presence' are seen as part of nursing practice (Benner 1984, Pettigraw 1988, Pettigraw 1990, Gilje 1992, Mohnkern 1992, McKivergin & Daubenmire 1994, Osteman & Schwartz-Barcott 1996, Bernardo 1998, Minicuccie 1998, Doona et al 1999, Fredrikson 1999) however these concepts are not well analysed in the literature and it is not clearly defined how they presents themselves in day-to-day nursing practice. What is confusing is that the concepts may have various meanings for different authors. The expectations of the phenomenon as part of nursing practice are also reflected in professional guidelines for example "Caring for Scotland: The Strategy for Nursing and Midwifery in Scotland" (S.E.2001) states:

More than any technical or other kind of expertise, people value Nurses and Midwives because they are there and they care.

'Being with' is often connected with non-technical care rather than technical, but what this activity entails is not well defined. Despite the fact that it is seen as an important part of nursing practice and the nursing profession, it is not clear from the literature in what way this is evident in nursing practice. There is a tendency to gloss over the meaning of the phenomenon as is apparent in the statement above. My own research points out that it causes confusion to have an element of professional practice glossed over in this way because it is left open to interpretations that may not be made explicit. One of the contributions of this study is actually to go back to an original source of Saunders' writings to clarify the meaning of the phenomenon 'being with'

in the palliative nursing context and to investigate how this translates into day-to-day nursing practice within a palliative care setting.

'Being with' and Saunders' belief

Saunders, in the 1960s, challenged the conventional health care system in the way that they cared for dying people and she developed a framework that would provide a better way. Through her work she raised awareness of the needs of dying patients which were not being met by professionals within the health care system in the late 1950s and early 1960s. The attention that Saunders paid to the care of dying patients consisted of two main components; firstly, her research in relation to the systematic use of morphine. With this Saunders prepared the ground for symptom control in palliative care as it is practised today –focusing on managing the symptoms of the disease in order to relieve suffering⁶. Secondly, Saunders' underpinning philosophy challenged the isolation surrounding a dying patient due to fear and the taboo around death and dying. It is this latter aspect that inspired my own practice as a palliative care nurse in Iceland and is the heart of this study. Saunders' writings present her ideas of 'being with' the dying patient with her 'facing of death' thesis. For Saunders, 'being with' would facilitate a dying patient's adjustment to imminent death, which she believed was a better way to die, and would include awareness and acceptance of the patient's imminent death.

Awareness of death

Telling the truth

When developing her framework, Saunders identified that dying patients had needs that were being neglected by health care professionals because of a sense of failure in not being able to cure the patient. This caused health care professionals to avoid the patient rather than be with him/her:

⁶ For a further account of how Saunders established this aspect of her work, see for example Saunders and Baines (1983), *Living with Dying: the Management of Terminal Disease*.

Death is feared, all thoughts of it are avoided and the dying themselves are often left in loneliness. Both in their homes and in hospital, they are emotionally isolated even when surrounded by their families or involved in much therapeutic activity (Saunders 1965 p. 70).

The movement that started with Saunders' theory and laid the groundwork for the care of dying patients as it is practised today was, in her eyes, "a movement facing death and long term illnesses and bereavement" (Saunders 1984). Based on her experience of working with dying people, Saunders (1959, 1965a, 1969) believed that many patients were ready to face the truth of their situations and were relieved to have an opportunity to do so, and that this would reduce their emotional isolation.

The starting point for Saunders, in terms of helping patients to cope with their imminent death, was to tell them the truth about their own situation - a notion that was not common during that time. She claimed that one of the foundations of her philosophy was inspired by one of her patients, David Tashma, whom she met in 1947 when working as a social worker. When she met him he was close to death on a busy surgical ward.

I knew then the truth he was dying, which he did not. He needed skills which were not then available, but still more he needed a sense of belonging and somehow to find meaning (Saunders 1981 p.4).

Saunders emphasised that even though health care professionals would not be able to cure the patients and solve the problem of incurable illness, they would be able to be with the patient through the process of approaching death. She described one of the hospice ideals as "watch with me":

In watching we should learn not only how to free patients from pain and distress, how to understand them and never let them down, but also how to be silent, how to listen and how just to be there (Saunders 1965b p.1617)

Saunders believed that many dying patients knew the seriousness of their illness, whether told or not. Hence trying to deny what was imminent would only add to their distress. With her framework of caring for dying patients she suggested an open awareness of death. Referring to Parkes' (1978) work she suggested

[Health care professionals] can deal with a person honestly without moving directly into stark truth. We have to face death openly, what he wants to reveal of

his thoughts and try to meet him where he is, making as it were an alliance with him. He may say 'I am frightened' and we may hastily murmur 'Yes, of course' and change to some more cheerful subject. Yet the dying patient may fear many things and a more appropriate response may be 'Are you? Well tell me what you mean by that'. Encouraged to talk further, the patient will then express fears, some of which may be quite needless. Much discussion with the patient will continue to take place in the context of symptom analysis and control and when they feel free to express unrealistic fears we can provide reassurance. When they can share with us their realistic apprehension concerning dependence and loss we can help them to express the grief they feel at their own weakness and the partings that loom ahead. (Saunders and Baines 1983 p.10)

Saunders' idea of 'being with' is related to the notion of open awareness of death. In the late 1950s and 1960s the conventional way of avoiding confronting a dying patient with the truth of their situation was being challenged. Ever since, it has been accepted that 'not telling' the patient is the wrong approach towards caring for dying patients.

The work of Saunders and in addition work done by scholars such as Kubler Ross (1970,1975), Sudnow (1967), Glaser and Strauss (1965) and Hinton (1963) influenced how care for dying patients was perceived, and health care professionals in Europe and the United States were challenged to adopt a different view. The work of Kubler Ross in the United States was in a similar vein to that of Saunders in that they both highlighted the importance of the acceptance of death rather than denial⁷. They also shared the view that avoiding death was not a way to help dying patients; instead patients needed help to confront death. The British psychiatrist Colin Murray Parkes in writing to Saunders in 1966 said:

[Kubler Ross] is most interested in your work and fully agrees with you that it is possible for a person to feel "safe" despite the approach of death (cited in Clark 1998b p 53)

Kubler Ross (1970) developed her five-stage approach towards adaptation to death, which showed how a person could move through the five stages from denial to acceptance of death if the truth was disclosed. Saunders emphasised how people close to death could be actively involved in some control over their life and to some extent

⁷ For a more detailed account of Kubler Ross' work see her five stage approach to death in Kubler Ross E (1970) *On Death and Dying*, London, Tavistock/Routledge and Kubler Ross E (1975) *Death: The Final Stage of Growth*, New York, Touchstone.

over their death if told of their imminent death and supported through facing that truth.

Other work such as Sudnow's (1967) introduced the concept of "social death" by showing how a lack of openness about the patient's imminent death caused dying people to die socially before dying physically. This was due to the fact that because health care professionals avoided the issue of death and dying, they openly avoided, as much as they could, contact with the dying patient him/herself; this caused the patient to become socially isolated⁸. This work not only indicated that it would be better to disclose the truth of the situation but also suggested that not telling the patient could be harmful for him/her. Another argument was made by Hinton (1963) that showed that even though patients were not told and health care professionals thought the patient did not know death was imminent, patients would have a certain awareness of the truth as their own weak body told them.

Glaser and Strauss (1965) made an additional contribution to the argument that not telling the truth might be harmful for the patient. In their research they described the social organisation and management of dying in San Francisco. They identified four types of 'awareness context' which had consequences for the experience of dying patients: firstly, closed awareness, where staff kept patients ignorant of their impending death; secondly, suspicious awareness, where patients suspected that they were dying and tried to get staff and relatives to confirm this suspicion; thirdly, mutual pretence, where all parties knew that the patient was dying but did not acknowledge this to each other and continued to pretend that everything was normal; and lastly open awareness, where all parties knew that the patient was dying and therefore because of their openness were able to talk about dying. Glaser and Strauss (1965) pointed out that the degree of awareness affected the interaction between the patient and the health care professionals. Avoiding speaking about something that is as profound as one's death causes awkwardness and even distance in the relationship between the patient and health care professionals.

⁸ In the late 1950s and early 1960s it was not uncommon practice for dying patients to be in a single room at the end of the ward corridor with the door closed, and when doing the doctor's round, someone would say 'status quo' and the group of health care professionals would pass the room without going in. When the buzzer rang for that room the nursing staff would look at each other anxiously, as everyone was dreading going into the room.

Open awareness of death in modern palliative care

Saunders' work and the work of the theorists mentioned, influenced enormously the way dying patients were cared for during the 1960s/70s. When I entered the palliative care field in the early 1980s it was a commonly held view that dying patients should know the truth of their situation. Openness about issues related to the patient's imminent death was, from the beginning, explicitly incorporated into hospice care (McNamara et al. 1995) and is now well established in settings that provide care for dying patients and amongst the general population in the U.K. and U.S.A. (Seale et al. 1997). As Field (1996) points out, it is now the common view within the UK that open awareness is the desirable way for patients to experience being close to death, due to recognition of the fact that terminally ill patients benefit from such an approach.

The modern western idea of a good or 'happy' death, in which death is accepted and where 'the final stage of growth' through dying has been achieved (Field 1996 p.259).

It is also commonly accepted amongst practitioners in palliative care that a lack of openness about a patient's imminent death is ineffective, damaging and morally wrong (Field and Copp 1999). Before the 1960s there was a general belief that "not telling people they were dying could maintain the social fabric and allow things to continue 'as normal'". However after the 1960s the general belief is that:

Such attempts usually failed and so patient's isolation became compounded by feelings of anxiety, mistrust and abandonment (Field 1996 p. 257).

Since the 1960s, there has been a growing shift in the health care culture towards an increased 'openness' with regard to caring for dying patients in particular within the hospice setting.

Saunders believed that encouraging the patient to speak about what was in his/her mind would facilitate adaptation to their imminent death. That is, Saunders encouraged both the patient's and the health care professionals' acceptance of the fact that the patient was dying and that the issue of death and dying could be brought up

when interacting with each other. However Saunders suggested it would be the patient who would indicate his/her willingness, ability and need to do so. For her there was subtlety around the communication of sensitive and painful subjects such as death and dying. This has been described by later theorists in palliative care as “cues” that the patient gives health care professionals in order to “test the water”. The health care professional needs to respond to such cues so as to show that he/she is also willing and able to discuss the patient’s imminent death. If the health care professionals pick up the “cues” as Saunders suggested the patient could then take the next step and discuss his feelings and thoughts further (Faulkner and Maguire 1994).⁹

In this study I was aiming to investigate how this happens in day-to-day practice within a hospice. However, as will become evident in the interpretation of data in the following chapters, this openness to discussing imminent death did not happen in the day-to-day nursing care. There was evidence that the patient’s doctor had told him/her the prognosis, that is, they had a terminal illness that was incurable. However this fact was usually not discussed with the patient by the nurses or the nursing care assistants when providing the day-to-day care. On the contrary the nurses and nursing care assistants avoided discussing the patients’ poor prognosis. As will become evident to the reader later in this thesis, it was the way the nurses cared for the patients that excluded an open awareness of death and dying. The nurses/ncas in the hospice where I conducted the study practised ‘mutual pretence’ (Glaser and Strauss 1965). That is, there was a certain social fabric created that allowed for death to be excluded from the reality of the hospice. The way the nurses/ncas constructed this will unfold in the following data chapters (chapters, 4, 5, 6, 7) and be discussed in chapter eight.

⁹ Within modern palliative care, communication has been given much attention and is seen as a big part of the skills needed for palliative care practitioners. Faulkner and Maguire (1994) were instrumental in establishing ways to teach communication skills.

Good death and open awareness of death

Preparing for death

In Saunders' view patients needed to be told that they were close to death because they could prepare for death. To know that death is coming gives an opportunity for the patients and their families to prepare for the patients' departure from this world and it is clear in Saunders writings that her view was such that being able to prepare for death was a better way to die.

Many deaths are sudden and give no opportunity for facing and coming to terms with what is happening. Such an unprepared entry into another world, and a judgement to face there, has been greatly feared in the past. But even where there is not belief in another life that demands some preparation, there is surely still a place for completing work on this one. This time would often be used for final summing up of what life has meant and for reconciliation and meetings that can make a major difference to the family's journey through bereavement (Saunders 1984 p. 297).

I think it is particularly important to try to help a dying parent to say "Goodbye" to the children. I have seen mothers with quite young children saying "Goodbye" not in so many words, but deeply all the same. I have two tape recordings of patients, one in her forties leaving two children who had both been problems and another separated from her husband, leaving a son about sixteen. They both say the same words, repeating before they died "I've done what I can". (Saunders 1969 p.56)

To know that death is coming gives an opportunity for patients and their families to prepare for the patient's departure from this world which can help the family as well as the patient. Even though death cannot be avoided, there are still things that a patient can make choices about, for example, how he/she would like to spend the life that is still left and about arrangements that will need to be made after he/she has died. In my own practice I have seen this in several forms: patients writing letters to small children that they can read when they are older; making financial arrangements; getting married; going to places they wish to visit before they die. It may also involve a patient choosing where he/she wants to die and even arranging their own funerals by choosing songs and making plans for the service etc. For preparation for death to happen the dying person would have to know that he/she was dying and "at least some truth of the situation has to be shared" (Saunders 1984 p.299).

Personal growth

Saunders also believed that death could be a positive thing since facing death might open up possibilities for the patient that otherwise would remain undiscovered and this is very evident in her writings. She believed that personal exploration about one's life and death would bring opportunities for personal growth because by saying "yes" to one's own dying the person could find new and creative life (Saunders 1986):

Life has many losses, many deaths, but they can become new beginnings even adventures, once they are accepted (Saunders 1986. p.1336). The last stage of life is not merely a time of negotiation but rather an opportunity for positive achievement. One of the ways we can help our patients most is to learn to believe and to expect this (Saunders 1965a p. 70).

Saunders believed that death could bring something good and should not be looked at as a negative aspect of human existence. She acknowledged that knowing one is dying might cause distress for the patient, but health care professionals, with a certain approach, could help the patient come to terms with things that might need sorting out before he/she died. Saunders felt that health care professionals could help patients to find out how to gather the scattered fragments of what looked like an unfulfilled life into a whole at its ending, and through this to find meaning in life and perhaps hope in death itself, as she did with her patient, David. Saunders claimed that David, and in fact many of her other patients, taught her a lot about the needs dying patients had and she claims in her writings that she saw lots of her patients grow personally through facing death (Saunders 1965a, 1981, 1986).

By accepting death the patient would be able to benefit, even though it might be painful, because they would be able to prepare for death and they would gain personal growth through that experience. She believed that open awareness of death as an approach to imminent death would be more fulfilling for the patient since they would be able to finish their own life, and they could retain some control.

Saunders believed that facing one's death would not be easy for patients to do and she described the process of coming to terms with the truth of death as a journey.

We may face death intellectually [but] we do not really imagine that we will die. A true facing of death is not done once for all, it is an individual journey for each person, a journey between those two statements (Saunders 1984 p. 296).

Saunders believed travelling between these two statements would be difficult for the patients, it would be “long journey of sorrow” and she suggested that health care professionals could have a role in assisting patients in undertaking this journey. ‘Being with’ plays a major part in this. It was for Saunders a way to help patients to prepare for their own deaths and she acknowledged that doing so necessarily involved the nurses sharing the truth of the situation, i.e. that the patients were dying. ‘Being with’ was for Saunders a way of doing this and of encouraging and helping the patient to come to terms with the painful truth.

Searching for meaning

Gordon (1997a), a hospice chaplain, has developed this notion of Saunders’ into the concept ‘finishing the business’. He explains it as

... [the need to] sort things out before [one] dies, “finishing the business”, concluding a search for meaning, purpose, fulfilment, finding an affirmation of the worth of [one’s] life. (Gordon 1997a p.19)

‘Being with’ is travelling together with the patient on his ‘journey to death’. As a result of ‘being with’ another human being, one can search for meaning, make sense of one’s life, as well as articulate longings by connecting with one’s own experience of life (Gordon 1997a, 1997b). Being able to gain a sense of order in his/her life through ‘telling their story’ and searching for “unfinished business” gives the patient some control over their own death.

As Catterall et al (1998) point out, this approach to care is based on the belief of the psychiatrist Viktor Frankl (1959/1984) that by making sense of experience and by relating that to reality, one is seeking order which is a fundamental need of human beings. Drawing on Victor Frankl’s writings Saunders points out that all people need to have meaning in their lives and death can at first seem to destroy that meaning and be meaningless in itself. However she believed that something good could happen as a

result of accepting the challenge that facing death brings, namely to construct new meaning out of the situation that facing death causes. According to Saunders, the dying patient is facing the fact that he/she is ending relationships and responsibilities and the time that is still left can be used to heal bitterness and find reconciliation (Saunders 1984).

Death is a natural condition of human existence

In order to reduce the loneliness and abandonment that dying patients were experiencing in the late 1960s Saunders developed her idea of 'being with' in facing death which would lead to a better way of dying. She emphasised that death in itself did not have to be a horrible experience but could lead to something positive, and a person could grow through facing death and gain from that personally (Saunders 1969). Saunders not only encouraged health care professionals to see facing death as an opportunity for personal exploration and growth, she was also trying to normalise death and dying. Saunders emphasised that death in itself did not have to be bad by showing it was natural to the human condition. When discussing what death is, Saunders would often draw on images that referred to nature. This can be seen in her collection of poetry and prose that she gathered over the 40 years of watching people as they drew near to death. One of the poems compares dying with the sun that sets but comes up again; such an image represents death as a positive event that is not final. This may correspond to Saunders' strong Christian faith.

What is dying?: I am standing on the seashore. A ship sails and spreads her white sails to the morning breeze and starts for the ocean. She is an object of beauty and I stand watching her till at last she fades on the horizon and someone at my side says 'She is gone'. Gone where? Gone from my sight that is all; she is just as large in the masts, hull and spars as she was when I saw her, and just as able to bear her load of living freight to its destination. The diminished size and total loss of sight is in me, not in her; and just at the moment when someone at my side says "She is gone" there are others who are watching her coming and other voices take up the glad shout 'There she comes.' That is dying. (Source unknown; published in Saunders 1990 p.45)

I can recall reading this poem myself when I was a palliative care practitioner many years ago. The message it spoke to me remains, namely, that death does not have to be a dark experience but rather can be bright as the sun. Saunders believed that if

health care professionals could adopt attitudes towards death that perceived death in a more positive light this would help patients to face their own death.

Saunders advocated a certain perception of death that she believed would reduce the isolation patients suffered from. By accepting death as a positive thing that is natural to the human condition and/or by seeing it as an opportunity for personal growth it would be easier to adapt to the idea of one's own death. Furthermore Saunders' attitude towards emotional suffering rests heavily on Christian principles. Based on her Christian view she stated:

God gave freedom of will and action to man and it is by his own misuse of this freedom that death and all that leads to it has been brought upon him. I do not mean by this that every illness is caused by the individual's wrongdoing but that disease and all our other ills were caused in the first instance by this sin of man. These things are permitted by God because He can use them to serve His own purpose and bring about an even greater good in the end. (Saunders 1959 p2-3)

For Saunders emotional suffering was not a bad thing. It served a purpose and had meaning. It would bring about something good in the end. Both from her Christian principles and for more secular reasons based on Frankl's work Saunders believed that suffering was not always bad and had a purpose.

'Being with' in facing death and suffering

Hence what Saunders emphasised was that death in itself should not be looked at as a negative event since that would cause the isolation of dying patients which would increase their fear of death. As a result of Saunders' work, which has spread across the world since the 1960s, hospice care practitioners were encouraged to adopt a value system that perceived death as potentially good rather than bad, as Aranda (2004) points out:

The binary opposition is that society generally sees death as a negative experience, while palliative care nurses have adopted a value system that reappraises the meaning of death in a more positive light, a natural part of life and not inherently negative (Aranda 2004 p. 626).

Within her framework Saunders wanted to shift the attitude to death from something that is negative to something more positive in order to reduce the isolation that dying patients suffered from. However as Aranda (2004) points out, this may actually conflict with negative emotions that death and dying provoke, as well as how death is viewed in society. The positive image of death that Saunders emphasised is not always easy to sustain in day-to-day work as workers are likely to feel pain as bonds with family and patients are broken down by death.

Saunders did acknowledge that facing death would be painful, however she still believed that accepting death was a better way to die because it would bring something good in the end, namely the opportunity for the dying person to grow in patience and courage. A large part of her work emphasises that health care professionals should not deny patients that opportunity (Saunders 1959). Saunders' model of care and her advocacy of open awareness of death was more inclusive of painful emotion than health care professionals caring for dying people were used to prior to this work. Facing death would certainly include painful emotions and thoughts. For her that would be an unavoidable aspect of caring for dying patients since 'being with' in facing death could be uncomfortable:

The dying person is facing a whole series of endings, of physical independence, of relationships, of hopes and future plans and of confidence in the meaning of life (Saunders 1984 p. 298).

This is recognised within palliative care today since seeking order through the messiness of dying can be painful due to the loss that one is facing.

On that journey, woundedness, suffering and mortality occupy special places, raising ultimate questions concerning the ontological meaning of life (Wright 2001 p.145).

This journey from intellectual knowledge of death to emotional acceptance would cause the patients emotional pain because it would be hard to come to terms with the belief that one's life was coming to an end. However, as noted, Saunders justified this pain by the fact that it could bring something good in the end. For Saunders this painful process and emotional suffering in relation to one's own imminent death could not be eased by the same approach as physical suffering.

The giving of effective relief to all types of pain makes [caring for dying patients] an extremely rewarding field and in itself is a major form of support. Nevertheless, if we are to remain for long near the suffering of dependence and parting we need also to develop a basic philosophy and search, often painfully, for meaning in even the most adverse situations (Saunders and Baines 1983 p.66).

This would cause patients sadness and sorrow; however Saunders did not believe that patients should be spared this suffering.

I do not believe that we should step in and spare [the patients] the suffering we hate to see, for we are not in a position to know what a dying man may find of reconciliation and peace in his last days (Saunders 1959 p. 3).

Saunders' philosophy of caring for dying patients indicates that emotional suffering could only be relieved by fostering and encouraging the patient to go through emotional suffering, the emotional suffering dying patients engage with is a significant part of preparing for death. By realising the fact that one was going to die soon patients could be encouraged to make use of the time that was left in the way they wanted. In order to prepare for one's death one would have to accept that one was dying soon, and that would be an emotionally painful process which could not be diminished in the same way as physical symptoms could be relieved (Saunders 1959). 'Being with' in facing death would not necessarily be comfortable.

Staff pain

Saunders' way of encouraging dying patients to move from intellectually knowing of death to emotional acceptance through 'being with' in facing death would not only cause the patient to suffer. But, also the health care professionals who cannot be untouched by the emotional pain of the patient who is facing death. De Hennezel (1989 p.31) points out that this 'new' socialisation of the dying process demands recognition of its value, not denial. But it also places demands on the staff, such as to:

- Enter into relationship with the patients.
- Participate in the exchange required by the dying process.
- Be able to talk about and exchange their own conception of death and the process of dying, so as to identify the yardsticks, the markers which will help them to conceptualise their own practice.
- Accept being changed, because merely to manage the death crisis without letting oneself be transformed by it would block the dynamic of the process.

Hence the transformative process that Saunders pointed out could happen for the dying patient as a result of confronting death is a two-way process according to De Hennezel (1989). It does not only happen to the patient, it happens to the health care professional as well. It is generally accepted within palliative care that a nurse working in palliative care practice cannot be untouched by this process.

Saunders suggested that in order to 'mature' in a work such as caring for dying people one has to go through a similar process to the patient in terms of searching for meaning and making sense of the experience.

Staff members of all disciplines may find themselves suffering a process of loneliness and exhaustion, protest, anger and depression and will need to share this if they are to find their way through. Merely to deny or repress such feelings hinders any progress to dealing with themselves and hence better with others in the future. The resilience of those who choose and continue to work exclusively in this field is won by a full understanding of what is happening and not by a retreat behind technique. The initial impact of hospice work at first hand and the draining effect of its continual losses call for some form of team or group support. This may well need to be varied: a series of group discussions seems to have a natural term and later another approach is needed. Spontaneous meetings that arise among those closely involved as a team continue to offer the most reliable as well as the most prompt and pertinent support (Saunders, Baines 1983 p.66).

Rittman et al (1997 p.116) call this aspect of care 'death work':

Even while helping patients to live each day to the fullest, nurses are dealing with death. This everydayness creates opportunities for the nurse to face her or his own death as well as the patient's death. Therefore, the nurse engages death work through a certain projection of self as the meaning of life and death is considered on a daily basis.

This means that the nurses are inevitably exposed to the pain and suffering facing death with their patients may cause them; it can not be avoided.

Emotional suffering due to opening up to painful feelings was worth it for Saunders because both the patient and health care professional would gain from that. Hence she believed suffering in regard to being close to death was valuable and should not be avoided. Just as Saunders suggested that the patient would in fact benefit from this approach she believed that staff would also benefit from it despite the suffering it would cause them. In the same way that there was a meaning-focused coping strategy built into the hospice philosophy in relation to patients as described in this chapter, so

it was for staff. Just as facing death demands a difficult emotional journey for the patient which he/she will benefit from, so it will for the staff also.

The hospice movement massively influenced the expectations of care provided for the dying and put on the nurses caring for people with terminal illness the expectation that they would be able to handle human feelings and complex human situations, as Halldorsdottir and Hamrin (1996 p. 30) point out:

Nurses are the ones who should be able to hear about the hurt and the pain, of body and soul.

James (1986) in her doctoral thesis introduced the term 'emotional labour'¹⁰ within palliative care to describe the aspect of care that involves dealing with emotions:

In circumstances where one adult cares for another, the expression of emotions is a negotiated process involving a mutual sounding out of what is acceptable. Emotional labour is flexibly organised so that it can be responsive to the needs of others...It requires listening, being there, talking and waiting mixed with giving direction, advice or actively making plans (James 1989p. 21, 26, 28).

With her study she identified that if the nurse were to be involved in dealing with the patient's feelings this would constitute emotional labour. However the nurses in her study did not usually invest energy in such a relationship, on the contrary they downplayed the patient's painful feelings (James 1986). James points out how palliative care is a different type of work as it includes total care that is physical, spiritual, social and emotional and therefore inclusive of emotions such as anger, loss, despair, and frustration. Furthermore she points out:

[whilst] expression of such emotions can be painful to watch and awkward to respond to....they do not fit in with standard ideas of what should occur at the workplace nor with standard ideas of workplace skills. (James 1989 p20).

James (1989) points out that a hospice that is running its practice based on Saunders' ideology would include expression of emotions in regard to death and dying. However this may not happen in the way it is expected based on the ideology. My

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The concept of emotional labour was first described by Hochschild (1983) as a suppression of feelings in order to keep up an outward appearance of a warm and friendly manner to the person receiving service. Hochschild did not base her work on nursing care, but on the service provided by flight-attendants. James' (1986) use of the term is different as it includes dealing openly with feelings.

own thesis will suggest that this implemented approach inclusive of such emotions in caring for dying patients may be more complicated than was acknowledged by Saunders when establishing her framework.

It is important to note that when challenging the fear of death, Saunders with her approach demonstrates a consistency with some psychological theories that suggest that through self-actualisation a person can develop a lack of existential anxiety and a greater sense of transcendence, selflessness and relinquishment (Cobb 2001). As Walter (1994) points out, the palliative care approach as established by Saunders', is based on the expressionist model that:

Considers that emotions are 'bottled up' and not expressed will go sour, leading to depression or various other pathologies. (Walter 1994 p. 110)

Rittman's et al (1997) study suggests that the meaning of the experience for the nurse in this intensive relationship seemed to be an important part of their practice:

Meaningful engagement between the nurse and the patient involves a commitment by the nurse. Nurses described a conscious though fleeting moment, when they decided to become emotionally invested in knowing the patient and establishing a deep involvement while accompanying the patient on the journey into death. Reciprocity in the relationship is realised as the nurse tells of his learning and growing while the patient also benefited from the relationship. The reciprocity of meaningful and close bonds with dying patients provides experience for nurses that are not commonly experienced by most people in our society (p117).

The nurses seemed to gain meaning from this experience in that they invested emotional energy in the relationship with the dying patient. Furthermore Rittman et al (1997) suggest that the attitude that is necessary for 'death work' to happen develops over time and with experience:

Nurses develop comportment as they engage in the patient's journey and walk alongside the patient while dying. Nurses understand death and dying not as objective onlookers gazing at the meaning from afar but through situated understanding of self gained from being meaningfully engaged in caring for the dying patient. The development of comportment evolves from experience and occurs over time. (p. 116)

However Boyle and Carter (1998) claim that repeated confrontations with death and caring for dying patients is a reminder of their own mortality for nurses, doctors and other health care professionals and can lead to stress and anxiety.

Rittman et al (1997) did not report closeness with patients near to death as a stressful encounter. It may be that a meaning-focused coping mechanism helped the nurses in their study to make sense of the experience in the way Saunders suggested. Furthermore, it is widely recognised within palliative care that in order to be able to do 'being with' in facing death the nurses/ncas need to be comfortable with their own mortality. Only then will they demonstrate a willingness to undertake the painful journey with the patient that is necessary (Sherman et al 2005). This will enhance the nurses/ncas' ability to take the opportunity of encouraging the patients to undertake the journey from knowledge to emotional acceptance of death. Nurses need to have confronted their own feelings about death and dying, otherwise they will respond to them with avoidance and distance (Copp 1997).

I have formulated 'being with' in facing death based on Saunders' writings in relation to helping patients in preparing for death and finding meaning in their imminent death. Another aspect of 'being with' in facing death based on Saunders' notion of a better way to die also includes an act that is often described as 'just being with' or 'doing nothing' and refers to what I described in the introduction when giving an example from my own practice.

Just 'being with'

'Being with' might in fact look like doing nothing because there is no visible action happening apart from what Lunn (1993) defines as, just sitting with people in their pain with suffering and unanswerable questions. For me as a practitioner using the word 'just' contradicted the complexity of the act; it implied it was something simple. It was this contradiction that triggered my own interest in the phenomenon, since it did not seem to value the act appropriately. As a palliative care nurse I experienced it as a major component of palliative care. Using the word 'just' implied that it was of less value than something else, or that it amounted to 'doing nothing'. The way of describing the act as 'just' or 'doing nothing' may indeed be because the action of 'being with' is passive in comparison with doing action. As Cassidy (1988) points out:

In the care of the dying, as in many other fields of endeavour, there comes a time when the carer's hands are empty, when all the treatment manoeuvres have been explored, all the words of comfort said. It is then that one is left standing at the foot of the bed, useless, impotent, wanting more than anything else to run away (p.58). ...The dying know that we [health care professionals] are not God. They accept that we cannot halt the process of cancer, the inexorable march of that terrible army that takes over a human body like an occupying force, pillaging, raping, desecrating without respect and without quarter. All they ask is that we do not desert them....At this stage of the journey, of being there, of simply being: it is, in many ways, the hardest part. (p.64)

'Being with' in palliative care is an important part of the care, but is less active than other aspects such as physical symptom control. Cassidy (1988) appears to suggest that it comes last on the list, when nothing else can be done to offer comfort. In fact the way she describes it, it appears as doing nothing.

It may be that 'being with' is seen as inferior to doing something that is more visible for the patients. Lee (1987) suggests that the word 'just' is used in a deprecatory sense. It may be that the act of 'being with' in facing death is seen as doing something that is of lesser value than taking some visible action that ensures comfort.

'Being with' versus 'doing for'

Saunders' work gave health care professionals "tools" to work with by focusing on symptom control and 'being with' in order to convince health care professionals that they still had a role in caring for patients with incurable disease. They were not 'doing nothing' when caring for dying patients even though they could not cure them. To highlight this Saunders developed her notion of facing death as described in this chapter that was, according to her belief, a better way to die.

Benner (1984) in her seminal work '*From Novice to Expert*' indicated that 'presencing' as a quality of 'being with' a patient is part of the expertise of a nurse. Benner makes a distinction between doing and being by using the term 'just being with' that is not focused on performing any act other than listening to the patient. It is interesting to note that for Benner it takes the self-esteem and self-confidence of an expert nurse to enable her to see that 'being with' is of value even though it does not include active intervention in solving something or doing something for the patient.

She describes this act as a 'person to person' contact. This was confirmed by two chaplains, working within hospice and hospital care, with whom I had a discussion during my Masters programme when I asked them what it took to do 'being with' in this way. They both said that it involved being confident and believing that this act was of value.

I have considered the meaning of 'being with' based on Saunders' notion of a better way of caring for dying patients. I will now turn to discuss how this would appear as part of nurses' role in day-to-day palliative care practice.

'Being with' in the context of nursing practice

The nurse as part of a team

Saunders believed that in order to care effectively for dying patients a team of multi-professionals was needed who would share their skills in the effort of caring for the dying patient. In fact one major part of Saunders' notion of a better way of caring for dying patients was teamwork and as Clark (2000a) point out this may be related to her own background.

Certainly, [there] emerged from Cicely Saunders' unique experience as nurse, social worker, and physician the remarkable multidisciplinary platform from which she launched the hospice movement (Clark 2000a p 1.)

In regard to the notion of 'being with' Saunders did not state that it should be any particular health professional who would do 'being with', but that it would be a shared responsibility of the team. Saunders developed the concept of total pain in order to emphasise the emotional suffering that imminent death might cause a patient. The idea she developed was the perception of a pain that would not only have a physical cause but a spiritual one, a total pain, related to the fact that a person's life was ending.

Crucially total pain was tied to a sense of narrative and biography, emphasising the importance of listening to the patient's story and of understanding the experience of suffering in a multifaceted way. The concept of total pain reflected

Saunders' willingness to acknowledge the spiritual suffering of the patient and to see this in relation to physical problems...By the mid eighties total pain had become firmly established as a central concept within the emerging palliative care speciality and was proving a useful concept in clinical work in teaching and (to a lesser extent) research (Clark 2000a p 1 and 4)

In an observational study of day-to-day practice, exploring the concept of 'total care' in a hospice, Vivat (2004) found out that within the hospice setting there was a clear division of labour among the multi-professional team. Different health care practitioners had a clear idea of what was their job and what was not. However within this job division few of the health care professionals working in the hospice saw the spiritual aspect of care as part of their job.

So, most workers in St Z's did not perceive that their work involved anything spiritual. Although workers generally stated that the spiritual dimension of care was important, and they were aware that it was part of the philosophy of hospice care, few workers felt that they personally were expected to, or competent to, deliver spiritual care. They perceived that attention to patients' spiritual needs was someone else's responsibility, although they were vague about whose responsibility this was. (Vivat 2004 p. 311)

Most health care workers did not feel they were either expected or competent to deliver spiritual care as part of their practice. Even though the idea of hospice care today is still based on Saunders' idea that caring for dying patients facilitates a good death or, as McNamara et al (1995 p. 231) put it,

Ideally all hospice patients should die a 'good' death. Hospice environment would run effectively and meet the criteria of their objectives if all patients and their families accepted and prepared for impending death and finished all the business in due time.

Vivat (2004) points out that the health care professionals knew of the notion of spiritual care as part of their practice but they did not all feel they should be doing it.

It may be that there are certain conditions required for 'being with' as facing death to happen. These conditions are usually not connected with professional skills but rather humanistic skills such as genuineness, mutual respect and empathy that are based on the relationship with the patient. For example Lunn (1993 p.216), who worked with Saunders at St. Christopher's Hospice, puts it this way:

The patient usually needs the combined presence of a team that goes beyond their particular skill and function. It is a skill and competence with a deeply human presence that is needed. Presence at its purest is being rather than doing so the

greatest test is whether we can just sit with people in their pain, with their suffering and unanswerable questions.

Lunn (1993) also points out that this aspect of care is not related to any specific profession of the health care team that cares for dying patients. To avoid confusion with religious care which would be done by a chaplain, a clear distinction is made between religious care and this notion of Saunders'¹¹, which is normally labelled spiritual care within modern palliative care. (Gray 1994, Simsen 1988, Wright 2001)

Both Saunders (1959) and Lunn (1993) point out that this aspect of care is a remit of nursing. It is generally acknowledged within palliative care that palliative care nurses should provide spiritual care (Simsen 1988, Grey 1994). For example Sherman et al (2005 p. 94) point out how nurses are well placed to engage with the patient's experience, which is what I was looking for in my research.

Dying is a time to reflect on the life lived, the relationships developed, and accomplishment achieved, as well as acknowledging unfulfilled hopes, dreams, or expectations. Nurses and other team members can assist patients, as well as family members, to process related thoughts and feelings, celebrate life achievements, and reframe missed opportunities or disappointments that can exacerbate suffering. This is often accomplished through a process of life review during which time the nurse communicates an interest.

Sherman et al (2005 p.94) point out that the nurse has a role in facilitating unfinished business in order to encourage patients to make their own choices.

With an awareness of impending death, patients are able to consider where they want to die, who they want to be with them, and how they want to die, and nurses can advocate these preferences.

Donna et al (1999) describe this as 'attentive attitude' that aims to 'connect to the patient experience'. Once it has been negotiated that the nurse and the patient are both available for interaction to happen where emotions are being expressed, the next step is according to Saunders to encourage the patient to tell his/her story by listening.

¹¹ See for example Lunn's (1993) division of spiritual and religious care where spiritual is much broader than religious and there is only partly overlap between the two. For her spiritual care is: the essence of what it means to be human and it relates to one's own personal meanings and values and relationship with others, self and God. For her religious care is: outward expression and systems of belief.

The relationship that is represented with 'being with', 'presence' or 'being there' in the nursing literature is based on a person-to-person relationship that is flexible in nature. In the same way as Saunders emphasised the need of dying patients to be listened to, 'being with' is represented within the nursing literature as a certain relationship that offers the patient the opportunity to tell his/her story in order to express his/her feelings and concerns.

By deliberately connecting with the patients, the nurse wants to understand the meaning of the experience for them (Appleton 1993 p.895).

For Saunders 'being with' consists mainly of listening to the patient's story and she considered this could be done by nurses.

...nurses who have time and heart to listen will have all types of problems, mental, moral and spiritual, brought to them (Saunders 1959 p. 10).

'Being with' as listening

For Saunders listening was a big part of her notion and 'being with' the patient was achieved through listening.

However, if we can come not only in our professional capacity but in our common, vulnerable humanity there may be no need for words on our part, only concerned listening. For those who do not wish to share their deepest needs, the way care is given can reach the most hidden places. Feelings of fear and guilt may seem inconsolable, but many of us have sensed that an inner journey has taken place and that a person nearing the end of life has found peace. Important relationships may be developed or reconciled at this time and a new sense of self worth develops. Those of us who have spent time in the company of people with mortal illness have learned from them what we are always challenged to know more and to help more effectively but above all, to listen. Sometimes there will be no answers to give those in an apparently desperate situation and we find ourselves with nothing to offer but silent attention. (Saunders 1996b in Kearney p. 11)

Nurses in Dunnice & Slevin's study (2002) described listening as an essential skill when caring for people with terminal illness. Listening became the key to discovering the patient's real wishes, thus facilitating their movement towards a peaceful death.

Listening is an important part of palliative care and a core component of 'being with' in facing death. Health care professionals can be there and listen by offering skills that

are based on their humanity rather than any professional role. Doona et al. (1999 p.59) emphasise that listening means understanding the patient's experience and the effort involved

...balancing multiple sources of data and, at the same time shifting them, weighing them, and trying to determine what is really going on in the patient situation....

This indicates that whilst the nurse is listening to the story she is making sense of what she is hearing. Doona et al. (1999) stress that in order to listen the nurses should not attend to anything else at the same time. The nurse shows availability by being less focused on tasks in order to be able to use her/his own mind and feelings to understand what is going on for the patient:

With nursing presence, nurses are less focussed on tasks...[she/he] sits with the feelings, her [his] own feelings and those going on in the situation and really slows down. (Doona et al 1999 p.59)

Fredrikson (1999) describes how listening is an act that enables the nurse to enter another person's world by listening to the patient in a certain way. This is a common notion in palliative care practice; by sharing the experience the nurse is able to enter the patient's world and hence 'be with' them. This includes paying full attention to what the patient is saying. Listening of course means more than receiving sounds and words. It demands a conscious effort where the nurse is searching for meaning and trying to understand what is said. Hence, listening is even more than taking in what is said but also involves interpretation and understanding of what is said. The aim is to share in the inner feeling of the other person (Fredrikson 1999).

Both Fredrikson (1999) and Doona et al (1999) show how listening to the patient demands full concentration from the nurse, and it is not possible to do something else at the same time. Hence, when doing my own study, I was expecting to see the nurses/ncas slow down, maybe sit down and not do anything else when this type of interaction happened.

What I have already stated is that 'being with' is about listening. It is linked to the notion that sharing the experience of what the patient is going through has value for him. Paterson and Zderad (1976) introduced the concept of "presence" into nursing

with a theory influenced by existential philosophy. They claim 'nursing is an experience lived between human beings':

Nursing comes into being because in a certain situation one human being needs help and another human being gives that help... Nursing is an existential engagement directed toward nurturing human potential... Nursing is concerned not only with well-being, but also 'more-being'. (Paterson and Zedard 1976 p. 3,15).

This links with Saunders' idea that by being able to share the experience of what is happening when someone is terminally ill and close to death nurses/ncas can turn death from being something perceived as negative to something good such as opportunity for personal growth.

'Being with' and flexibility

Within the nursing literature the phenomenon 'being with' is often described as flexible in its nature, i.e. in order for it to happen a non-routinised care is required. For example, Fredrikson (1999) described 'being with' as being based on

intersubjectivity that is grounded in mutual receiving, the nurse and the patient are not only present to each other as roles, but in addition are present as whole persons. (P 1171)

Forrest (1989) describes 'being there' in this way:

Putting the patient before routine... attending to the individual request, a physical and emotional presence that says to patients you are there all day for them (p.819).

Liehr (1989) points out that it is the patient's agenda that is in the forefront of the interaction, and it is the patient's mood that is the focus of the interaction.

True presence is an experience of genuinely engaging with another, perhaps for only a fleeting moment, perhaps intermittently for an extended time. While one's own worries and interest drift into the background, the person with whom one is engaging moves to the foreground with all the anger, joy, fear, or pain the shared moment may hold. To attend in this way, the nurse's sensitive awareness of the other extends beyond the content of verbal interchange. (p 7.)

In her ethnographic study where she was focusing on how death and dying were managed within a hospice, Mazer (1993) found that nurses in her study did not

practise the hospice ideology in relation to open awareness of death. When she spoke to the nurses they knew of the ideology but they did not give this aspect of palliative care priority. Routine physical care was prioritised leaving little time for other aspects of care. Both James (1986) and Mazer (1993) found that physical care was prioritised over emotional care, thus leaving patients' emotions in relation to death and dying unrecognised within the nursing care. Mazer's (1993), James' (1986) and Vivat's (2004) studies point out that there is a gap between the ideology and reality in regard to the aspect of care that I am studying. In my own study I will consider this gap. I found out in my own study that the ideology of palliative care did not match day-to-day reality and in the beginning of the study I felt that 'being with' was missing from the care. However, as I aimed to understand the nurses' and nursing care assistants' understanding of 'being with' I started to realise that their understanding was different from mine which was based on Saunders' ideology as discussed in chapter two. Hence in my own study I offer an understanding of the *constraint of the ordinary routine*, that allowed 'being with' in facing death to remain absent without this being noticed. 'Being with' was constructed as providing comfort since this fitted better into the way the care was organised as well as the ethos of the care. Furthermore it allowed the issue of death to be avoided.

'Being with' and the traditional health care system

Playle (1995) argues that nursing care differs from medical care in the sense that nursing has traditionally aimed for holistic care with the focus on individuals, but that task-orientation is the product of the dominant biomedical model within health care. Saunders' framework of a better way of caring for dying patients reflects the emphasis on the nurse-patient relationship that has historically been highlighted by nursing scholars such as Peplau (1954/1988), Ferlic (1968) and Vailliot (1966) as an important part of nursing in the 1960s, and later by scholars such as Watson and Roxie (2003) and Jonsdottir et al (2005) in the early and mid 2000s. It is not my intention with this thesis to explore how the concept 'being with' has been part of the debate of what is the essence of nursing. However I would like to mention that some authors such as these above had advocated for the phenomenon 'being with' as an important part of nursing. Furthermore I would like to point out that there is a certain level of subjectivity and abstractness within Saunders' concept of 'being with' and the

way the above authors describe nursing. This has not always fared well within a health care system that has been geared towards technical developments in relation to health care (Sandelowski 1997).

Saunders (1993) pointed out that a response to pain based on the illness-cure biomedical model is different from the response based on a model that not only emphasises physical aspects of care but also spiritual, emotional and social aspects. She developed a concept of total pain, which explores the patient's discomfort on the basis not only of physical reasons but also of other domains such as the patient's mind and emotions.

Based on the model of total pain Kearney (2000) differentiates between these two responses. Some pain may be responsive to the intervention of the medical model and is analysed, understood and treated through a logical process that will change and control events. However certain types of suffering are not responsive to this paradigm. The main element of the medical model is searching for objective signs of disease, which is then diagnosed and treated. Kearney (2000) describes a model that he calls the 'unnamed' model of healing as

an approach that lessens the suffering and helps that individual to endure, live with and hopefully, in time, live through that suffering (Kearney 2000 p.15)

He emphasises that this approach is not based on rational thinking, analysing or understanding but on a more psychodynamic approach that has to do with the intuitive and unconscious aspects of the mind. This indicates that 'being with' does not sit easily with the traditional medical model.

It is possible that Saunders realised that in order to establish a systematic way of caring for dying patients that was fundamentally different from the mainstream health care system, she would only be able to achieve that by moving out of that system. This she did by establishing an independent hospice. She in fact stated that she moved out of the NHS in order to be able to have the freedom to develop her own way of caring for dying patients. By moving out of the NHS and establishing an independent hospice, Saunders was able to practise a different approach to the care of

dying patients including 'being with' in facing death. Saunders also claimed that she moved out of the NHS with a view to introducing her approach into the NHS once she had established it (Du Bovlay 1984, James and Field 1992). Modern palliative care has moved into the mainstream NHS (Hockley 1996). However it may be that within a health care model that emphasises cure and a high technical approach to care, 'being with' in facing death is hard to sustain since it demands such a different approach from care of the traditional model.

'Being with' and Heidegger's work

Within the nursing literature there are nurses like Nelms (1996) Parse (1992,1997) and Doona et al (1999) who emphasise that 'being with' or 'presence' require different approaches than are traditionally adopted within the modern health care system. As Doona et al (1999) phrase it, it requires the nurse to go 'beyond scientific data' when trying to connect with patient experience. Nelms (1996) and Parse (1992, 1997) describe a specific relationship as an important part of nursing practice and draw on Heidegger's philosophy to explain how nurses in relating to the patient may be using knowledge that is intuitive and embedded in their own beings. These authors, in explaining this relationship draw on Heidegger's notion of human beings as interpreters, that is, it is through understanding an experience that we as human beings gain knowledge. A nurse/patient relationship is for these authors based on striving for an understanding of the needs of the patient as a human being which may be very individualistic for each patient. The interaction between the patient and the nurse is based on the nurse trying to understand the patient's experience of being ill and she/he trying to engage with this experience.

Parse (1992 1997) emphasises the term 'dwelling with' as a certain quality of the relationship that will foster understanding of the patient experience. Interaction between the nurse and the patient happens when the patient shares his/her experience, meaning is interpreted and understood, and this leads to personal growth. Parse in her theory development draws primarily on the existential phenomenological hermeneutic thought of Heidegger, Sartre, and Merleau-Ponty where the main focus of the nurse/patient interaction

requires seeking understanding of lived experience. (Parse 1997 p. 330)

For her, the aim of the relationship between the nurse and the patient is for the nurse to understand the patient's situation, rather than make an impact on it. Her theory, 'human becoming theory', explains this as:

[The nurse] dwells with the person as they uncover the meaning in a situation, synchronize rhythms and move beyond. (Parse 1992 p.41)

Based on Heidegger's notion of interpretation Parse (1992,1997) suggests that when a person is faced with a new experience he/she tries to find the meaning of that experience, to interpret the experience and intergrate that experience as part of his being which leads to 'more being'. For Parse this can happen when the nurse 'dwells' with the patient enabling the patient to find new meaning through his/her existence in new circumstances. If the patient is able to reflect on and make sense of his experience he can re-evaluate his 'being'. Parse calls this a therapeutic relationship based on the positive outcome for the patient of 'more being'. (1992. P39-40)

Nelms (1996) also draws on Heidegger's philosophy when explaining 'being with' in nursing practice as 'presencing oneself'.

Presencing is the gift of one's self in human interaction and requires receiving another's presence as well as giving one's presence. (368)

Nelms analyses stories from five nurses, based on Heidegger's philosophy of human existence, and argues that the nurses responded in an ontological way to the ontological need of the patient. The interaction is based on the humanistic need, that is, the need for empathy, genuineness, mutual respect and joint participation (Playle 1995).

Based on my own reading of Heidegger (1962) for this thesis I would like to consider critically how Nelms (1996) and Parse (1992,1997) use Heidegger's work to explain the relationship between nurse and patient. According to Heidegger (1962), when we

are born we are 'thrown into the world' without any knowledge of who we are or what the world is about. We learn to understand the world and ourselves as humans through experience. As we live our lives we learn by interpreting this experience. For Heidegger this is the essence of human beings. By interpreting experience it is understood and incorporated into one's own being or *Dasein*¹² and this makes up the essence of *Dasein*.

Dasein involves the interpretation and integration of phenomena in the world into one's own being through experience. Interpretation gives us the ability to understand the world we live in and through this interpretation we know how to 'be-in-the-world' (Heidegger 1962). Therefore as humans we are constantly dialoguing with the world as we interpret and understand phenomena and this makes us who we are, *Dasein*.

Parse (1992,1997) interprets Heidegger's ideas of human beings being in the way that interaction between a nurse and a patient aims to allow patient expression of his/her experience. Parse's (1992, 1997) theory shows how nurses play an important role in helping patients to make sense of what is happening to them and to use that experience to grow into 'more being'. Parse describes how the nurse is not meant to make any impact on the patients but only to listen and enable patients to find their own meaning. According to Heidegger finding one's own authentic meaning does not happen in relationship with others, nor does the development of self in an authentic way, because of the power of the publicly interpreted way of understanding phenomena in the world. This according to Heidegger is not possible since in relationship with each other we always share an interpretation of the world. In order to be able to authentically consider one's life through the interpretation of experience he believed that one had to be alone.

Nelms (1996) uses Heidegger's notion of being authentic when relating to what the patient needs. To describe what happens in a nurse/patient situation when the nurse draws on intuitive knowledge Nelms (1996) draws on Heidegger's concept of a 'silent call from conscience'. That is, the action of the nurse in the situation is based on a 'silent call from her conscience' that is authentic and based on each individual nursing

¹² *Dasein* is the term that Heidegger uses to describe human beings as interpretative beings.

situation in the sense that the response from the nurse may be different for each individual. However, according to Heidegger (1962) the silent call that Nelms (1996) describes is impossible to follow when the nurse/nca has to fit into a group of nursing staff that have organised the care in a certain manner because of the way the world is commonly interpreted. According to Heidegger authenticity is only possible when one is alone and away from the way the world is commonly interpreted. Hence it may be unrealistic to expect that the intuitive nursing situation that Nelms (1996) is describing would happen in a day-to-day ordinary situation of nursing care practice. Hence the nurse/patient experience that Nelms (1996) is describing may have to be considered as exceptional experience rather than what one would expect to happen on a daily basis.

Because of the way the world is commonly interpreted, Heidegger's theory suggests that a relationship between the self and other is such that the expression of self in an authentic way never happens in relationship with others. It is exactly this point in Heidegger's work that will be used in chapter eight to understand what was happening in the field in relation to how the phenomenon of death was dealt with by the nurses and nursing care assistants. For Heidegger human beings or *Dasein* do not have the ability to experience and interpret the phenomenon of death into their own beings because once *Dasein* has experienced death, *Dasein* is dead. However *Dasein* has the potential to interpret and understand the phenomenon *anticipating the possibility of death as certain* and by doing so it becomes incorporated into *Dasein*. Heidegger's notion suggests that death is publicly treated in a way that encourages people to avoid rather than face it. This conflicts with Saunders' theory of facing death as discussed in this chapter, and her work effectively challenged Heidegger's theory. In chapter eight I will, in the light of the data collected in this research, revisit Saunders' notion of 'being with' in facing death as formulated in this chapter and I will also discuss further Heidegger's notion of how human beings can or can not face death.

Conclusion

I have in this chapter formulated 'being with' in facing death based on Saunders' notion of how to provide better care for dying patients. I have shown how this relates to an open awareness of death that allows for the preparation for death and gives the opportunity for personal growth in the last stage of life. I have formulated my own understanding of the phenomenon 'being with' as it was prior to the study based on my reading of Saunders' work. I have established my own understanding of 'being with' in facing death that includes a certain availability, listening, and an open awareness of death. This for Saunders was an important part of palliative care since it allowed for preparation for death which was in her understanding a better way of dying.

With this research I wanted to observe and describe how this would happen as part of day-to-day nursing practice. I have pointed out that 'being with' may be an approach where the nurse is using intuitive knowledge and is flexible in her/his engagement with the patient. Also this approach may differ from the dominant disease-cure model that is dominant within the health care system. It became apparent in my own study that the nurses did not do 'being with' in facing death as part of their day-to-day nursing practice. This will become evident to the reader in chapters four, five and six. Hence the focus of this study shifted from looking at how the nurses do 'being with' in facing death to considering why they do not. What this thesis mainly turns to deals with is the fact that 'being with' for Saunders was related to open awareness of death. With this study I will show that facing death may be very difficult for the nurses and the nursing care assistants to do because of the emotional demands that facing death involves.

In this chapter I have shown how nursing scholars, in explaining emotional interaction between nurses and patients, have used Heidegger's work. I have pointed out that my own reading of Heidegger takes a different point from his work, namely the fact that phenomena in the world are publicly interpreted and this inhibits individualistic understanding. For Heidegger the understanding of phenomena is always publicly interpreted when in a relationship with others. This I will expand on in chapter eight

in relation to how the phenomenon of death is publicly interpreted and this will suggest why 'being with' in facing death may be avoided by the nurses and nursing care assistants.

In the following chapters (four, five, six and seven) the reader will be invited to see how 'being with' was constructed in the field where I did my study and was in fact differentiated from the way I have formulated the phenomenon in this chapter. The argument that developed through doing this research is based on the fact that 'being with' was constructed differently in the field where I did my study from the way it is formulated in this chapter according to Saunders' notion. But it is the research approach that the next chapter turns to.

When considering what methodology to adopt for this research I was keen to be able to adopt an approach that would enable me to capture how 'being with' happened in day-to-day practice. In the next chapter I will explain my methodology that enabled me to understand how nurses and nursing care assistants do 'being with' in practice.

CHAPTER THREE

Researching 'being with' in nursing practice

Introduction

In this chapter, I will discuss the methodological and analytical approach that helped me arrive at an understanding of how the phenomenon 'being with' appeared in relation to day-to-day nursing practice in the hospice where I conducted my study.

As noted in chapter one there was a contradiction between the way the phenomenon 'being with' was described in day-to-day language, and how I valued it; that caused me concern. It triggered the interest in this research and I wanted to describe how 'being with' appears in nurses' day-to-day work, in order to make it explicit how this phenomenon occurs. The main focus of the study was to understand how nurses do 'being with'. However in doing this research, I was also aware of my own preconception of 'being with' that I brought to the research, as discussed in chapter two. For this study it was important that I adopted a methodology that would allow me to reach a comprehensive understanding of 'being with' as it happens in day-to-day practice, and at the same time take into consideration my own preconception of the phenomenon that triggered the research.

'Being with' taken for granted in practice

I am investigating a phenomenon that is an aspect of nursing which is abstract, hard to measure, intangible, and non-technical. This may be reflected in the fact that when exploring the nursing literature for the concept of 'presence', it was noticeable that there seemed to be a gap in the discussion of this aspect of nursing practice in the 1970s. It may have been tempting for nurses to pay less attention to this aspect of

practice during a period of time when the focus in general within the health care system was on technical intervention and improvements. During this period, nurses were preoccupied with describing nursing in relation to their role that focused on technical skill and knowledge (Sandelowski 1997). This may have shifted the focus substantially to the technical aspect of nursing in order to gain status in a technically driven health care system (Sandelowski 1997). For the last two to three decades various nursing scholars have paid increasing attention to the nurse/patient relationship as something unique to the nursing profession. What may have inspired modern nursing scholars to refocus on issues related to the abstract relationship between the nurse and the patient in the 1980s was the qualitative approach that was being introduced in nursing research. This approach to research may be better equipped to capture the nature of the unique relationship between the nurse and the patient in a systematic way than the quantitative approach which had been dominant prior to the 1980s (Playle 1995).

Nursing is a practice-based discipline and there is increasing interest amongst nursing scholars in capturing the knowledge that originates from practice. 'Being with' as a phenomenon is an example of such interest. Nurses have been increasingly interested in focusing on the patients' experience of being ill, the relationship between the nurse and the patient and the contribution nurses are making with their practice in this context to research inquiries. In the late seventies and early eighties it became an increasing trend in nursing research to investigate the practice of nursing in order to describe its unique knowledge base that is believed to be partly embedded in practice. Benner's (1984) work is highly influential here. She describes how a novice nurse becomes an expert through experiencing practice. In her work she pays attention to the knowledge embedded in nursing expertise, and in doing so, describes the essence of nursing and nurses' unique knowledge base.

Benner's (1984) research approach, phenomenology, became a promising approach for nurse researchers interested in capturing the unique knowledge base of nursing embedded in practice. Phenomenology has its roots in the work of Merleau Ponty, Heidegger, Husserl and Schutz. The research approach that developed out of such a philosophy aims to capture the experience that is created as human beings interact with the world. By understanding the meaning of an experience a phenomenon can be

understood. Knowledge generated by this research approach is based on the interpretation of the meaning of an experience. This research methodology provided a radical shift from the traditional methodology for science, namely, the positivist approach. That is based on empiricist epistemology, related to natural sciences, which seeks to generate laws and to explain reality through finding a truth rather than understanding meaning within experience (Booth et al 1997). Many nurse researchers favour a methodology within the interpretative tradition rather than positivism¹³.

This study focuses on the 'taken-for-granted phenomenon' of 'being with' which is embedded in practice. Hence I considered an approach within this phenomenological tradition to capture the knowledge that might be embedded in the nurses' experience in order to generate understanding of the phenomenon. The approach that I adopted for this research is based on the phenomenological tradition. What I found helpful when aiming to capture a phenomenon as it happens in day-to-day practice was ethnomethodology. One of the main differences between ethnomethodology and the phenomenological approach adopted by Benner (1984) is that the focus of the investigation is based on actual practice as it happens rather than what the researcher is told about practice. What was also important for this research, since I did not see the nurses and nursing care assistants practise 'being with' in the way I understood the phenomenon as discussed in chapter two, was to adopt a way of interpreting what was happening based on the nurses' and nursing care assistants' understanding of the phenomenon as well as holding my own. For this I adopted Charles Taylor's (1985) philosophy of interpretation. Hence I drew on two main theorists to develop a research methodology necessary for capturing the nurses' and the nursing care assistants' understanding of 'being with' based on their actual practice while also holding my own understanding of the phenomenon. These are Harold Garfinkel (1967) who based his methodology on phenomenology and developed a research approach to encapsulate 'taken for granted knowledge' in practice which he called ethnomethodology, and Charles Taylor (1985) who helped me to interpret my data in a way that allowed for the nurses'/ncas' understanding of 'being with' as well as my own.

¹³ For further reading of the interpretative tradition within which this research sits see Crotty M (1998).

Garfinkel's Ethnomethodology

Garfinkel (1967) developed his research approach, ethnomethodology, in order to formulate how 'members' create a phenomenon in their day-to-day life. His work assumes that a phenomenon only exists in the context of the practice in which 'members' create it. In his development of ethnomethodology as an approach to studying 'taken-for-granted' knowledge embedded in people's behaviour, he draws on the social phenomenology of Schutz and Parsons' theory of action. Even though he was inspired by Parsons' theory of action in terms of focusing on how a phenomenon is created through action, he was also highly influenced by the interpretative philosophy of Schutz.

In Parsons' theory, the actors' motivation is integrated in normative models that regulate behaviours and reciprocal appreciations. This integration is what accounts for the stability of social order and its reproduction in every individual encounter. As Parsons would see it, we share values that are beyond that rule and us us. To avoid anguish and sanctions, we tend to conform to the rules of common life. (Coulon, 1995, p.3-4)

Garfinkel adopted Parsons' thought that there is an 'internalized system' that governs us and that we respect, to maintain order (Coulon 1995).

But ethnomethodology poses the problem differently [than Parsons' theory]: The relationship between actor and situation is not stable and unchanging, produced by cultural contents or rules; it is produced by processes of interpretation. (Coulon 1995 p.4)

Garfinkel draws on Schutz who believed that a common world was possible not because the experience of two people could be identical but because of 'idealizations' used by actors. It consists of two things, first the possibility of 'interchangeability' of perspective, that is, two actors can share their different perspectives by exchanging angles of view and secondly, 'conformity' to the system of relevance, that is, all members have a shared interest. By this permanent adjusting process of 'idealizations' a common world is possible (Coulon 1995). For Garfinkel the 'real world' is made up by its members, and there is a structure to how it is made up that makes social life possible. As a sociologist he was interested in how social life was made possible, and

he believed that there was an order to social life that was invisible to its members but possible to capture as it appeared in the members' actions.

In doing sociology, lay and professional, every reference to the "real world" even where the reference is to physical or biological events, is a reference to the organized activities of everyday life (Garfinkel 1967 vii).

He developed ethnomethodology in order to show how it was possible to capture the organised world by focusing on people's actions. He believed that through such a methodology it was possible to identify the reference they were using to make social life possible.

Ethnomethodological studies analyze everyday activities as members' methods for making those same activities visibly-rational-and-reportable-for all-practical-purposes. (Garfinkel 1967 vii)

I was inspired by Garfinkel's ethnomethodology. My study aimed to explain the phenomenon 'being with' as it happens in nursing care day-to-day practice in a hospice in Scotland. My intention with the study was to explore what I considered as 'taken for granted' in the ordinary day-to-day life of the hospice nurses/ncas' practice. I saw a clear parallel between the aim of my study in capturing 'taken for granted' knowledge which was embedded in the actions of 'members' in 'being with' and Garfinkel's research approach to identifying the reference people use to make social life possible:

[Ethnomethodology] seeks to treat practical activities, practical circumstances, and practical sociological reasoning as topics of empirical study, and by paying to the most commonplace activities of daily life the attention usually accorded extraordinary events, seek to learn about them as phenomena in their own right (Garfinkel 1967 p. 1).

For Garfinkel a phenomenon is interrelated with the web of day-to-day life that exists within the ordinary life of its members. I considered the phenomenon 'being with' as 'taken for granted' in our day-to-day work and I found that it related to Garfinkel's notion of how members of society can go about their day-to-day affairs by drawing on background features of everyday scenarios.

The member of society uses background expectancies as a scheme for interpretation. With their use actual appearances are for him recognizable and intelligible as the appearances-of-familiar events. Demonstrably he is responsive to this background, while at the same time he is at loss to tell us specifically of what the expectancies consist (Garfinkel 1967 p. 37).

Garfinkel (1967) suggests that there is a source of knowledge embedded in human beings, that people draw on in their everyday life, which is collectively constructed. He developed his methodology, applicable for social sciences, based on the belief that a phenomenon is a feature of social constructions. However Garfinkel suggests that usually members are not interested in reflecting upon background knowledge or expectation but use them as a reference in their day-to-day encounters.

For members to be "interested" would consist of their undertaking to make the reflexive character of practical activities observable (Garfinkel 1967 p. 9).

As said in the beginning, I became interested in describing the phenomenon 'being with' when working as a palliative care nurse. However the other members of the team I was working with were not particularly interested in making the activity observable as Garfinkel suggests. I considered it problematic that we were not able to describe the phenomenon in another way. Firstly, I thought the phenomenon was being undervalued when compared with technical intervention and this troubled me. I thought it might make nurses less confident when 'being with' if it was seen as of less worth than some other activity. I considered that there was a unique knowledge base embedded in the nurses' behaviour when they practise 'being with' that was 'taken for granted' and not articulated. Hence my starting point for this research was exactly the way in which the ethnomethodologist would start his/her inquiry namely, by being interested in reflecting upon 'taken-for-granted' knowledge in order to reveal that knowledge. This interest is different from that of 'members'.

The special motive of the interested member is exercised to arouse the disinterested member by pursuing conditions that express contingent and problematic nature of common convention (Blum & McHugh 1984 p. 88).

For Garfinkel (1967) a phenomenon, as part of day-to-day life, becomes a matter of investigation. That is, the ordinary is made extraordinary for its features to emerge. This was again what I was aiming for: to make something that seemed to be an

ordinary everyday event in my own setting, as it was talked about, and make it into something extraordinary. This was, for Garfinkel, a task for the social scientist. It was not something that a 'member' of the setting could do themselves because they would not be aware of the resources they were drawing on in their actions.

Ethnomethodology [is] the investigation of the rational properties of indexical expression and other practical actions as contingent ongoing accomplishment of organized artful practices of every day life (Garfinkel 1967 p. 11).

Ethnomethodology views humans as active in the process of creating the social world based on how they make sense of it as members. For Garfinkel, humans are sense makers or interpreters; however it is not possible for them to be aware of this as it happens. Garfinkel developed ethnomethodology in order to do so.

Garfinkel (1967) believed that members could not articulate the background knowledge that they were drawing on in making up the social world; however they would make this visible to each other through their actions.

Activities [,] whereby members produce and manage settings of organized everyday affairs [,] are identical with members' procedures for making those settings "accountable". (p.1)

'Accountable' for Garfinkel means (1967)

Observable-and-reportable, i.e. available to members as situated practices of looking-and-telling. I mean, too, that such practices consist of an endless ongoing, contingent accomplishment that are carried on under the auspices of, and are made to happen as events in, the same ordinary affairs that in organizing they describe (p1)

Ethnomethodological inquiry explores how members produce the phenomenon that is under investigation through the method of observation. The underlying belief is that a social scientist can capture the construction of a phenomenon by observing how members make the phenomenon apparent to each other. Hence, this differs from the interview setting where the social scientist has identified the phenomenon as his/her starting point and then theorises about it through the interview process. The starting point for the ethnomethodologist will always be practice with no theoretical assumptions about the phenomenon. The ethnomethodologist will not have expectations of a phenomenon as a starting point but will be interested in how



members create the phenomenon through their actions. For Garfinkel human beings make up society through their actions. As a sociologist he was interested in investigating this process. This makes Garfinkel different from other sociologists who follow the interpretative tradition of social science. He was even interested in how the commonplace is possible rather than what the commonplace is.

Although sociologists take socially structured scenes of everyday life as a point of departure they rarely see as a task of social inquiry in its own right, the general question of how any such common sense world is possible. Instead, the possibility of the every day world is either settled by theoretical representation or merely assumed. (Garfinkel 1967 p. 36)

For ethnomethodology, members' interpretations are embedded in their behaviour. They remain unnoticed and unseen because they are 'taken for granted', expected, ordinary activities embedded in day-to-day encounters with the world. For Garfinkel, people are not asked for an account of what they did or didn't do unless that is out of the ordinary. An account is given only of things that go wrong or occur in a way that is not expected. For Garfinkel, to ask a person for an account of the ordinary would be impossible because we don't usually analyse the ordinary. Members express their mutual assumptions to each other through their actions and behaviour which are observable but not talked about because they are taken for granted. It is only when something unexpected happens that one is asked to be accountable. For Garfinkel, it would be impossible to interview someone about an ordinary activity. Hence, ethnomethodology favours observation within the situation.

What was helpful for the development of this research was the notion of Garfinkel's methodology of capturing how members in their cultural and social environment construct the meaning of a phenomenon which becomes visible through their actions. By observing their actions the collective taken-for-granted knowledge is identified and it becomes evident how the phenomenon is constructed in the nurses/ncas' day-to-day practice. I favoured Garfinkel's approach as this gave me the opportunity to observe how the nurses/ncas constructed the phenomenon of 'being with', that is how it happens in practice. Through using observation to collect data based on Garfinkel's methodology I identified that 'being with' as I understood it was not happening in their routine practice. Observing practice as it actually happens in the way it is

constructed through members' behaviour may produce different data from interviewing members about their own practice.

In interviews, the danger is that subjects may tell the researcher what they want to hear-that is, what they think the researcher wants to hear-that is what they think they should do in a certain situation and not what they actually do (Swanwick 1994 p. 4).

Looking at people's behaviour gives an account of what people actually do rather than what they say they do. Hence observation enables researcher to see first hand how participants perform rather than relying on self-reports (LoBiondo-Wood and Haber 1997). Furthermore, with the method of observation for data collection individuals can be observed in the context where the phenomenon under investigation happens in order to reveal their understanding of the phenomenon (Garfinkel 1967). By observing how the phenomenon is constructed in the actual environment through people's behaviour, it is possible to describe how it presents itself in ordinary practice.

By using interviews rather than observation in a research on a phenomenon that is acknowledged within palliative care such as 'being with' it may be that participants would tell the researcher what they know about the phenomenon rather than actually how it presents itself in their everyday work. What they tell the researcher might not necessarily reflect ordinary practice. They might give an account of how they do 'being with' by giving one or two examples, however these might not necessary reflect common practice. People usually don't give an account of the ordinary because it is taken for granted. When asked to talk about certain aspects of their work, people want to talk about something that is extra-ordinary otherwise they might think it is not worth mentioning. Furthermore, what is ordinary is often taken for granted and not noticed. People are often not able to give an account of what is ordinary because they have not noticed it themselves. Observing the participants is likely to produce data that describes their actual practice that they may otherwise find difficult to articulate.

In an interview setting participants might look for highlights in their practice or something outstanding to describe the phenomenon rather than how their understanding of the phenomenon is transparent in their day-to-day practice. It may be necessary for researchers who are interested in describing nursing practice to avoid using only nurses understanding of a phenomenon as it is revealed in the interview

setting as it may describe the highlight of their own practice rather than ordinary practice. Researchers who are relying on interview data only in describing phenomenon in nursing practice (based on nurses understanding), may have to be cautious and not assume that what is described is an understanding of a phenomenon as it appears in every day practice. Interview data may reflect a more strongly theoretical account rather than actual practice. Due to the research methodology adopted in this study, my own observational account reflects nurses/ncas' understanding of a phenomenon based on their behaviour and attitudes as observed. Observational data allows the researcher to identify what is happening in a given context (Jorgensen 1989) and one of its main advantages is that information can be collected on a wide range of activities including characteristic of the environment and culture (Polit et al 2001). In this study, this became highly relevant in terms of understanding of the way 'being with' is constructed in practice.

Ethnomethodology has not been used as much as phenomenology in nursing research. However such a methodology has the potential to describe knowledge based on a discipline that members of that discipline use on a daily basis. Hence it fits research that aims to capture the epistemology of practice rather than theoretical knowledge. Bowers (1992 p.65) points out that ethnomethodology as a research approach has the potential to

Show how the social institution of nursing is constructed, accomplished and brought off as a methodic production by individual nurses.... it would be possible to describe the intricate web of behaviours through which nursing is constructed.

The intention of this study is to explicate how nurses/ncas in a hospice setting interpret 'being with' dying patients. By applying the principles of ethnomethodology I was able to investigate how the nurses and the nursing care assistants practise 'being with' patients as an organised activity which is constructed by them within the day-to-day context of their environment. The way they had constructed this activity was different from Saunders' notion of 'being with' in facing death. By observing the nurses and the nursing care assistants I paid attention to the meaning of the phenomenon 'being with' as it was constructed by them within the context of their day-to-day practice, and can describe this in my study even though they could not articulate it themselves since it was taken for granted.

Even though ethnomethodology informed the research in terms of observing how members did 'being with', I discovered that it was not totally appropriate throughout the whole research process. If I were to follow Garfinkel's ethnomethodology when interpreting the data, I would focus only on the way the members understood the phenomenon 'being with' or the way they made the phenomenon observable to each other. Ethnomethodology as developed by Garfinkel did not allow for an interpretation based on my own notion of the phenomenon 'being with' as it focuses only on understanding the members' actions, based on their conception. The aim of ethnomethodology is fundamentally descriptive. It speaks for practice rather than to practice, and through reflection it mirrors practice (Blum and McHugh 1984). However, it represents the members' understanding without any critical analysis of their understanding and behaviour.

*Ethnomethodology seeks to 'rigorously describe' ordinary usage...
Ethnomethodology conceives of such a description of usage as analytical
solutions to their tasks (McHugh et al 1974 p. 22).*

With the ethnomethodology developed by Garfinkel (1967) it is inappropriate to critically analyse the behaviour of the members. Such an approach is only meant to describe. Interpretation in ethnomethodology is based on trying to understand members only through their own self-understanding.

I was committed to the phenomenon of 'being with' in the way I understood it based on Saunders' notion of 'being with' (as formulated in chapter two). I had a presumption of how 'being with' should be done and discovering that it did not happen in the way I understood it made it important to understand how the nurses and nursing care assistants did it. It was possible to do this by using the ethnomethodological approach. However committed I was to the phenomenon of 'being with' in a certain way through my own practice, as a researcher it was also important for me to try to understand the absence of the phenomenon 'being with' that is, as discussed in chapter two, connected with an open awareness of death. By following only ethnomethodology I would not be able to reflect upon the absence of the phenomenon in the way I understood it.

Following the principle of interpretative research in being clear about my own intention (Emerson et al 1995) I reflected upon what was happening when I did not see what I was expecting to see in the field. Realising that I had a different understanding of the phenomenon than the nurses and the nursing care assistants at the hospice where I conducted my study made me want to take my own understanding of the phenomenon into the research. Being informed by Garfinkel's (1967) approach, I was committed to discerning and describing how the phenomenon was understood by the nurses and the nursing care assistants in the hospice. However what became apparent was that, because of my commitment to the phenomenon in the way I understood it, I wanted to be more critical in my interpretation of how the phenomenon was observable in the members' behaviour than ethnomethodology would allow. Not only did I want the practice to speak but I also wanted to speak to the practice based on my own knowledge. This is where Charles Taylor's (1985) work became an important part of my research.

'Understanding' in Taylor's work

The tension between what I saw in the field and my own expectations of the phenomenon became methodologically functional by adopting Charles Taylor's (1985) work of understanding in the social sciences. Being informed by his approach to interpreting data enabled me to see and understand the way the phenomenon 'being with' was constructed in the field, as well as hold on to my own understanding when interpreting the data¹⁴. With this approach I was interpreting not only in relation to my own understanding but also to the nurses/ncas' understanding. This was crucial in

¹⁴ Reading Bonner's (1998) paper also helped me in achieving this. In his paper he examines the kind of parenting developed by White in his well-known book "The First Three Years of life". In his examination of "White program of Effective Parenting" Bonner challenges White's argument of parents' availability for the demands of effective parenting.

In his analysis Bonner considers what is practically possible for the parent whilst also holding White's understanding of effective parenting. Reading this paper inspired me to challenge my own understanding of the phenomenon 'being with', that was based on Saunders' ideology of 'being with' in facing death, by being informed by practice. By being informed by practice I started to consider what was practically possible for the nurses and nursing care assistants to do compared with what was ideal practice based on my understanding of Saunders.

terms of rigorously representing the nurses/ncas' understanding even though I would also draw on my own understanding.

One of the main principles of understanding in the social sciences according to Taylor is

An adequate account of human action must make the agents more understandable.... We make sense of what they did. And this means that we come to see how as agents-i.e., beings who act, have purposes, desires - they came to do what they did, and to bring about what befell (Taylor 1985 p. 116 and 117).

Taylor emphasises that interpretative social science is about understanding our participants. However, he makes a clear distinction between empathy and understanding in social sciences. 'Human understanding' for Taylor (1985) is 'discursive understanding', not just a matter of feeling empathy in the sense of being on the 'same wave-length' with someone or having a kind of 'unformulated pre-understanding' of them. I could relate to this with the participants in my study. I did not feel empathetic towards them at the beginning of my data collection. I was surprised on many occasions to see how they related to the patients because it was so different from what I expected and so different from how I conceived palliative nursing practice. I found it helpful to follow Taylor's approach in trying to understand the nurses even though they and I differed in our understanding of 'being with'. In order to be rigorous in my analysis of the data I realised I had to understand why they acted in the way they did.

What I adopted from ethnomethodology was that theoretical accounts are about being able to formulate what the agents were doing based on their own self-understanding. Members might not be able to formulate it themselves through their own self-understanding because some of what they feel, desire, etc. will be unexamined. However, as a researcher, I believed that with this research approach alone I would not be able to adequately describe the phenomenon. Adopting Taylor's (1985) approach, in addition to ethnomethodology, allowed me as a researcher to not only understand the nurses and the nursing care assistants in the way they understood themselves, but to challenge their understanding through my own.

Simply recovering [the members'] self-description may cast no light at all on what was going on. It would make [social science] illuminating, since in many

cases actors are confused, misinformed, have contradictory purposes, and their language may reflect this. The starting point of scientific effort may be that we find something perplexing in their action as they understood it. (Taylor 1985 p. 117)

What was perplexing in terms of the self-understanding of the members I was researching, was that the nurses/ncas had asserted that they were doing 'being with'. I had told them that I was interested in the phenomenon 'being with' and gave them examples from my own practice that represented how I understood the phenomenon. They all agreed that this was their understanding of the phenomenon as well, therefore I expected to see them 'being with' in the way I understood it throughout the observation period. However, though I was observing for several months I did not see 'being with' in the way I understood it. This became the starting point of a scientific investigation and the main focus of this study became what was going on in relation to the phenomenon 'being with', rather than just a description of how the members constructed the phenomenon. This made it impossible for me to follow only the ethnomethodological principle of describing the 'members'' understanding. As noted I was committed to my own understanding of the phenomenon 'being with' and to understanding its absence in the field where I did my study.

Taylor's (1985) approach informed me that the starting point in my interpretation of the data would be understanding the 'agents'' understanding of 'being with' in the same way as ethnomethodology did. In addition, based on my experience and knowledge, I might assess how 'being with' happens or does not happen in the nurses/ncas' practice. However, according to Taylor (1985), if I did that by basing my interpretation only on my formulation of the phenomenon, without trying to understand them, I would assess them on an 'irrelevant ground'. I would be criticising them without understanding them. I would be imposing my understanding on them in a way that obscured their understanding as 'agents'.

Suppose [the subjects] offer very different, even incompatible, views of the world and of the subjects' action? Does the scientist have the last word? Can he[she] set the world-view of his subjects aside as erroneous? But to condemn this world-view does he [she] not have to stand outside it, and is this external stance compatible with understanding their self-definitions? (Taylor 1985 p.116)

For Taylor (1985), how to deal with this difference between the social scientist's understanding and the members' understanding was one of the main issues of the

debate around *verstehende* social science. His view is that interpretation leading to an understanding of the agent is neither an account based merely on the agent's perspective nor an account based merely on the social scientist's perspective.

What is demanded of a theoretical account is that it make the agent's doings clearer than they were to him.... Understanding someone cannot simply mean adopting his point of view, for otherwise a good account could never be the basis for more clairvoyant practice. (Taylor 1985 p. 118)

Being informed by Taylor's theory of understanding in social sciences was important for my ability neither to base my interpretation only on the nurses/ncas' self understanding nor to draw solely on my own understanding when analysing and interpreting the data. Because I am a palliative care nurse with experience of 'being with' and theoretical knowledge of the phenomenon, I made assumptions about how I would see it in practice. Therefore I felt something was missing from the day-to-day nursing practice when I did not see the phenomenon of 'being with' happen in the way I expected. This was important, but should not overshadow the way I interpreted what was happening in the field, which was how 'being with' was understood by the nurses/ncas at the hospice where I was conducting my study. One of the main intellectual challenges of doing this research was to live with the tension between my own understanding of the phenomenon and the nurses/ncas' understanding without letting one overshadow the other.

The theoretical knowledge that this study unfolds is neither my understanding of the phenomenon nor the nurses' and the nursing care assistants' understanding of it. By aiming to understand their perception but also to challenge it and allow their understanding to challenge my own I reached a certain understanding of 'being with' in the way the nurses/nursing care assistants did it and also a realisation of the absence of 'being with' as I understood it. For Taylor the language of theoretical knowledge based on understanding another culture is neither the researcher's language nor the members' in the culture the researcher is investigating:

The error in [the] view [of understanding in social science] is to hold that the language of cross-cultural theory has to be either theirs or ours. If this were so, then any attempt at understanding across cultures would be faced with an impossible dilemma: either accept incorrigibility, or be arrogantly ethnocentric. But as a matter of fact, while challenging their language of self-understanding, we may also be challenging ours. Indeed what I want to argue is that there are

times where we cannot question the one properly without also questioning the other. In fact, it will almost always be the case that the adequate language in which we can understand another society is not our language of understanding, or theirs, but rather what one would call a language of perspicuous contrast. (Taylor 1985 p. 125)

When I entered the field, I had a preconception of the phenomenon. Following the ethnomethodological approach of not having identified the phenomenon but instead seeing how the members constructed it in their day-to-day work meant that it evolved in a different way than I expected. Following Taylor's philosophy I would not adopt only their understanding nor would I just interpret what was happening based on my own understanding. In the interpretation of what the nurses/ncas were doing in relation to the phenomenon of 'being with' I aimed to understand what they were doing and feeling and how that could be seen as 'being with' according to their understanding. For Taylor (1985) only such an interpretation would be convincing. It meant taking into account the actions and ideals of the members. I had to challenge their understanding of 'being with', although in doing so I also challenged my own understanding. This thesis is not only about 'being with' as they understood it nor is it about 'being with' as I understood it. It is in Taylor's terms developing a 'language of perspicuous contrast'.

Such a language of contrast might show their language of understanding to be distorted or inadequate in some respects, or it might show ours to be so (in which case, we might find that understanding them leads to an alteration of our self-understanding, and hence our form of life-a far from unknown process in history); or it might show both to be so. (Taylor 1985 p.125-126)

Earlier in this chapter I discussed how I discovered that I could not follow the ethnomethodological approach of using only the members' understanding in theorising about the phenomenon, as I felt that would not give an adequate account of it. And this made me adopt Taylor's philosophy of understanding in social sciences. Because I had my own understanding and preconception of the phenomenon I could not accept the actors' understanding. However I had to understand them to avoid criticising them on irrelevant grounds.

We do not see them as just making a set of scientific/technological errors. But we can criticize them. For the separation perspective has in certain respects shown its undoubted superiority over the fusion perspective. (Taylor 1985 p.129)

The description of 'being with' as presented in this thesis is in a 'language of perspicuous contrast' in which I have understood 'being with' as happens in the nursing practice where I did my study in relation to my understanding of 'being with' (Taylor 1985). By adopting this approach I would both understand the nurses/ncas at the hospice but also have to consider my own understanding of 'being with', even though these two differed. By understanding the nurses/ncas' construction of the phenomenon of 'being with' I had to reconsider my own understanding of the phenomenon.

It will frequently be the case that we cannot understand another society until we have understood ourselves better as well. This will be so wherever the language of perspicuous contrast which is adequate to the case also forces us to redescribe what we are doing (Taylor 1985 p. 129)

It is common within nursing research for nurses interested in knowledge embedded in practice to use Gadamer's¹⁵ notion of dialogue as developed from Heidegger's philosophy. Taylor (1985) acknowledges that the notion of language of perspicuous contrast is very close to Gadamer's conception of the 'fusion of horizons'. However Taylor (1985) also points out that his own approach to understanding in social science avoids the pitfall of what he calls 'incorrigibility'. For Taylor an adequate description of a phenomenon is based on dialogue that reveals contrasts rather than bringing about fusion as for Gadamer.

Our account does not have to be in the language of understanding of the agent's society, but rather in the language of contrast. And the agent's language clearly is not taken as incorrigible. At the same time, we are not committed to ethnocentric course (Taylor 1985 p. 126)

Taylor believes that a more critical view of our members and also ourselves than Gadamer's fusion of horizon suggests will lead to a better understanding of practice.

We are always in danger of seeing our ways of acting and thinking as the only conceivable ones. That is exactly what ethnocentricity consists in. Understanding other societies ought to wrench us out of this; it ought to alter our self-understanding. (Taylor 1985 p. 129)

¹⁵ See Gadamer (1975/1989) *Truth and Method* and

Warnke(1987) *Gadamer: hermeneutics ,tradition and reason.*

For Taylor such an approach provides social theorising that is situated in practice and can free us from misconception about practice. For Taylor (1985) understanding is inseparable from criticism but in turn also inseparable from self-criticism.

We can see how explaining another involves understanding him. And at the same time, it can give us some insight into the complex relations that bind explanation and self-definition, and the understanding of self and other. (Taylor 1985 p. 130)

In this chapter I have discussed how initially my research approach was informed by ethnomethodology. That involved suspending my own understanding of the phenomenon 'being with' as for the ethnomethodologist it is important when entering the field of study not to have the phenomenon in place and then theorise about it, but to have as a starting point how the phenomenon appears in practice, and to observe how the phenomenon is made evident by the members in their day-to-day affairs. Secondly, I followed Taylor's approach of seeing analysis in the social sciences as more critical for understanding than ethnomethodology which aims at description. It is also more critical than Gadamer's 'fusion of horizon' as it can challenge both the members' understanding and the researcher's understanding. I will now turn to discuss the research process.

The research process

Ethical issues

It transpired that I did not need to seek formal ethical approval for this study as my study was an observation on non-NHS staff. Despite this I was aware of ethical concerns related to doing an observation study and especially within the hospice setting. It is well known within palliative care that conducting research involving patients close to death needs considerable sensitivity (Costello 2001). Not having formal ethical approval in fact increased my own sense of responsibility and concern for the patients and staff at M Hospice. While doing my research I was always concerned about the vulnerability of the setting and the trust that the managers and the nurses/ncas had in me. This gave me a real sense of responsibility and concern for the patients and staff at M Hospice. Vivat (2002) argues that ethics are "situated" and

advocates for researchers to adopt “contextualised” and “situated” approach in their research in order to maintain ethical research practice. She claims that abstract ethical considerations in the form of gaining ethical approval from a research committee may not be enough when conducting ethnographic study. The formal way of seeking ethical approval from research committees, rather than relying on researchers “situated” and “contextualised” approach is a framework for “detached ethics”. It does not take into account when doing observational study the researcher will continually have to make decisions/choices that are related to ethics.

I considered ethical issues in relation to the way it is formally considered (in negotiating access and informed consent) but I also considered ethical issues in my relationship with the patients and staff at M Hospice. During the course of the study I was constantly making ethical decisions when relating them. In regards to the patients this was similar to my 13 years experience of engaging with dying patients. The one issue I found was related to the fact that the nurses/ncas did not do ‘being with’ in the way I understood the concept. I was concerned when I saw them acting in a very different way from the way I would do. That was not doing ‘being with’ in the way I understood it. As a researcher, I was not meant to interfere with the way the care was normally carried out. However, on some occasions it turned out to be very difficult for me to watch the interaction without getting involved. I found it hard to see the opportunity for ‘being with’ in facing death to be missed and I do believe that some patients might have benefited from this approach. I did consider that the exclusion of ‘being with’ in facing death from the nursing care was the accepted standard of care. Everyone at the hospice, nurses/ncas, managers, patients and their relatives saw this as adequate care. I felt from an ethical point of view I did not need to interfere, however from a professional point of view as a palliative care nurse it was taxing on me too not to do so.

Another ethical issues came up in relation to the fact that even though the nurses/ncas knew what I was researching I considered that they actually may have had a limited understanding of what I was actually looking at and how I would process what I saw. Vivat (2002 2004) had the same ethical concerns during her study and found that people frequently asked her what she was doing, even though she had explained it before. This was not the case in my research, on the on contrary people never asked

me what I was doing as they seemed to know. It was their total trust in me that made me concerned that they did not know that I was actually not seeing what I was hoping to research. This ethical concern stayed with me until the end of my data collection when as an exit strategy I told the nurses/ncas and the managers about my preliminary findings and the fact that I had not seen 'being with' in the way I understood it¹⁶. However by making the decision to be committed to understand the nurses/ncas' understanding of the phenomenon 'being with' rather than only describe the phenomenon as absent I did maintain an ethical stance in my relationship with them.

Despite no formal ethical approval there was a process carried out that considered ethical issues especially in relation to negotiating access and informed consent that I will now discuss.

Negotiating access

In November 2001 I approached a hospice in order to gain access to a research site. First of all I contacted the medical director who arranged for me to meet with him, the nurse manager, and two nurses from the Education Unit at the hospice. At this meeting I outlined the main aims and the focus of my study. At the end of the meeting I left a written proposal and I also sent an information letter about the study to the medical director (appendix I).

A few weeks later I contacted the medical director to see if they had made a decision regarding my proposal. They were favourable towards my suggestions and I was asked to meet the charge nurse to arrange the practicalities of introducing the study to the nurses and nursing care assistants at the hospice. I had gained the manager's trust as a researcher and they had faith in my proposal. Vivat (2002) discusses the ethics of negotiating access and how this relates to the managers (that are the gatekeepers) trusts on the researcher. It may well be that knowing that I was a palliative care nurse with 13-years experience increased the managers' trust in me. I had also some international profile and the medical director was aware of this credibility. I also felt that one of

¹⁶ When interviewing and informally chatting to the nurse manager at the hospice I told her that I did not see 'being with' in the way I was expecting. Her response to this will be reported later on in this thesis.

the purposes of the meeting was to 'get to know me' and this might enable them to consider if I was trustworthy or not.

In order for the nurses/ncas (who would be the main participants in the research) to be able to consider if they agreed to allow me access to do my study I also had meetings with the nurses/ncas. The charge nurse set up three sessions where I would introduce my study to the nurses/ncas and they would have access to my research proposal. Most nurses/ncas at the hospice were able to come to one of the three sessions. The charge nurse then gathered information from the nurses/ncas about the general feel for whether they would be willing to participate. I spoke to her one-week after the last session and she said that her general feeling was that most nurses/ncas were positive about participating in the study.

Informed consent

Once the nurses/ncas had had the opportunity to consider my research proposal (for those who could not attend one of the three meetings I left a paper copy of my proposal in the nursing station). I went to the hospice to talk to the nurses and gather informed consents. Everyone agreed to participate in the study and signed the consent form (see appendix V). Despite the fact that I would not be involving patients directly in my study, as I was focusing on the nurses/ncas, I would of course observe their interaction with the nurses/ncas. By being allowed to observe the nurses I would be observing the patients. Gaining access to do an observation study in a hospice raises the concern of protection of people with impaired autonomy who are vulnerable because of their situation. However as noted I would be drawing on my sensitivity for the setting in engaging with patients based on my many years' experience of practice as a palliative care nurse.

The patients and relatives were informed of the study by a letter I wrote about my study. It was decided that the nurses/ncas would be responsible for handing out the letter to the patients/relatives (see appendix III). The managers at the hospice thought that this would be more appropriate than me giving patients/relatives the information sheet as the study did not involve the patients directly other than through me observing the nurses/ncas when caring for patients. If I approached the

patients/relatives to introduce the study it might indicate that I was asking for something from the patients (for example, asking for their opinion of the care) rather than permission to observe the nurses interacting with them. Therefore written informed consent was not gained from patients. The (2002) offers a critical view of the process of gaining informed consent from patients. Informed consent usually entails a patient being given a brief description of the study they are asked to participate in and then signing consent form usually after been given some time to think about if he/she is willing to participate in the study. The (2002) observed that patients usually agreed immediately to participate in a clinical trial proposed by their doctor and seldom asked any questions. The doctor did not go any great length in explaining the study. This raises the question of how many patients actually understand what they read before signing informed consent. The consent form is supposed to support the patient but handing out forms does not necessarily mean that the patient has read it or understood completely (The 2002). This point is supported by Vivat (2002 p.245) who argues

participants in- "subjects" of ethnographic research do not (indeed, cannot) ever really understand the consequences of what they agree to since it is impossible to fully anticipate what one will reveal or how the researcher will use it.

In my own study, every patient was asked for permission prior to me observing the nurse/nca caring for him/her without me being there when the patient was asked. All patients who were asked during the observation period agreed. The patients gave verbal consent rather than written consent. I was always introduced to the patients as someone who was doing a study looking at the nursing practice but that I was also a palliative care nurse.

I brought to the managers' attention that their informed consent for my study (appendix IV) could be reviewed at any time. We also agreed that if any concerns were raised either by members of staff, patients or relatives about the study, this would be discussed. After having collected data for about four weeks I had a meeting with the nurse manager to discuss any concerns which might have arisen during this period. He confirmed that I could continue with my data collection as no issues had come up in regard to me doing the observation in the hospice. During the observation period I had a number of meetings with the charge nurse, both formal and informal,

where we discussed 'how things were going'. There were a number of opportunities for the managers to raise issues of concern. However, not one of them had any issues during the period of data collection.

My role in the field

At my first meeting with hospice managers when negotiating access the nurse manager at the hospice said that I would have to be very close to when and where the physical care of patients happens. He also suggested that I would only see 'being with' if I participated, to some extent, in the day-to-day physical care. I was told that the nurses in this hospice usually worked behind screens and in order to see what happened, I would have to participate behind the screens with the nurses. This was what I discovered when I did a practice observation in order to try out the method (in a different hospice from where I collected data; data from this observation is not included in the study). I found out that it would be awkward to observe interaction between a nurse and a patient closely without some participation. What also became apparent to me when discussing my proposal with the hospice managers and educators was that both nurses and nursing care assistants provided the nursing care. Hence I decided to include the nursing care assistants in my study as it would be interesting to see if they did 'being with'.

It was common at the hospice to have 'visitors' in terms of nursing and/or medical students who would shadow members of staff. I asked the nurses/ncas to see me in the role of such a student who was learning from them how the care was provided. In order to keep my presence in the field less awkward, and in order to be able to see the nurses/ncas /patients' interactions I decided I would participate in the setting. I agreed with nurses/ncas that I would be 'helping out a bit' or be 'an extra pair of hands'. I would assist the nurses/ncas who were caring for the patients. For example, if two people were required to help the patient I would be the assistant to the nurse/nca and do what she asked me to do.

In deciding on my own role in the field I followed Spradley (1980). He describes four degrees of participation in observation depending on the level of the researcher's

involvement in the setting, with the least involvement as 'passive' and the highest as 'complete'. According to Spradley (1980) my own involvement was moderate, the second lowest of the four. For Spradley (1980) observing within this role for research purposes means maintaining a balance between being an insider and an outsider by both observing and participating.

You will have to maintain a dual purpose: you will want to seek to participate and to watch yourself and others at the same time. Make yourself explicitly aware of things that others take for granted. You will experience the feeling of being both an insider and outsider simultaneously. As you participate in routine activities, you will need to engage in introspection to more fully understand your experience (Spradley 1980 p.58)

I did not want to take part in or be responsible for any complex nursing activities that might take my attention too much away from the observing role. Hence I chose a role that would help me to fit into the setting but still keep my mind on observing and thinking about what I saw happening in relation to the phenomenon of 'being with'. I did not wear a uniform, because I did not want to participate too much in the setting. When I was working with the nurses/ncas around the patients I had an apron on to cover my clothes in the same way as the nurses/ncas covered their uniforms. I paid attention to wearing comfortable clothes and kept a low profile in order not to stand out too much from the staff when caring for the patients

Data collection

When collecting data I followed the ethnomethodological principle of not having the phenomenon in place and then theorising about it, but aiming to see by observing how the members made sense of the phenomenon. Hence in an ethnomethodological way I entered the field with an unstructured approach. My aim was to observe the nurses/ncas in their day-to-day nursing practice and see how the phenomenon 'being with' was constructed in their work. For Garfinkel (1967), in order to make the ordinary day-to-day activity extra-ordinary one has to be a stranger to the activity. I was not a stranger to the phenomenon of 'being with' as such since I had my own experience of it, but I was a stranger to how they constructed the phenomenon since I was not part of their setting prior to the study. The setting was unfamiliar to me. The language used was not my first language and was therefore unfamiliar to a certain extent; this made me give special attention to what was said. Taking on a role as

insider and outsider I avoided participating too much in the setting which prevented me becoming too familiar with the setting but allowed me to fit in so my presence in the field was less awkward. This, I believe, helped me to maintain an objective perspective when observing how the nurses/ncas in M Hospice constructed the phenomenon. I was also aware I had to suspend my own understanding whilst collecting data.

Observation

I started my observation in late April 2002 and it lasted until January 2003. In the beginning of my observation I was monitored as the charge nurse guided me into the field. I felt that it was her role to make sure that it was safe to let me enter the field. She suggested that I should begin the observation period by attending the multidisciplinary meetings. After that she passed me on to the nursing team leaders and for the next few days I followed the team leader of each ward, sat in on doctors' meetings, shadowed them as they cared for patients, and talked to the other members of the nursing team.

During the first couple of weeks of my data collection I was not around the patients much. I was mainly in the hallway and the nursing office. I felt that this was not very fruitful in terms of observing how 'being with' was constructed in the hospice. I was not involved in the care enough to be able to observe interaction between patients and the nurses/ncas. However I made use of this time to understand the physical setting and observe what happened in the nursing station. I also looked on this as time for the nurses/ncas to get to know me in order for me to gain their trust.

Trusting and co-operative relationships among the participant observer and the insiders in the field setting, in short, are necessary for unobstructed access to the daily existence of insiders and for accurate, dependable, high quality information about their world. (Jorgensen 1989 p.70)

In addition I used this time in the beginning, when I was 'just being around' without participating in the care, to take note of my initial impression. I noticed what was going on in general and how I felt about the place. I used it to orientate myself, to understand the physical construction of the place and who was who. I found this a good way to start a process that seemed a bit overwhelming (Emerson et al 1995).

After a couple of weeks in the field I wanted to move closer to the nurse/patient interaction in order to more purposefully observe how 'being with' happened. I realised that the nursing manager was right and that I needed to be close to the hands-on nursing care in order to see this happening. It was not uncommon during the morning to look into a 4-bedded room and only see the curtain screen around each bed to actually indicate that the nurse/nursing care assistant was interacting with the patient. Single rooms had a small window on the door which was usually covered with blinds when the nurses/ncas were caring for the patient in that room. Hence, after a couple of weeks of 'being around' in order to gain trust, I knew I had to move closer to the patients in order to see what was happening when nurses/ncas interacted with them.

I found out that in order to be close to the patients/nurses' or nursing care assistants' interactions, it was better to attach myself to one nurse/nursing care assistant in particular rather than just appear and 'be around'. I would usually ask a particular nurse/nursing care assistant the day before if I could shadow her/him for a period of time the next day while I was at the hospice for observation (usually 3-4 hours at a stretch). This was not with the aim of investigating each individual nurse/nca but it allowed me to get closer to patients' interactions. The nurses/ncas mostly agreed to this. However on two occasions the nurse/nursing care assistant that I had asked to shadow told me that there was actually not much to see. I accepted this as the nurse/nursing care assistant not wanting me to shadow her that day, and then asked someone else if I could shadow them, which was not a problem. By shadowing a particular nurse/nursing care assistant for each observation session, I had an opportunity to be in the patient's room and to go behind the screen close to the patient. I could observe the nurse/nursing care assistant that I was shadowing when she interacted with the patients. But it also allowed me to observe not only the nurse/nursing care assistant I was shadowing but the other nurses/nursing care assistants as well. I was at the heart of observing nurses/nursing care assistants interacting with the patients.

I was usually at the hospice for 3-4 hours per day, 2-3 days a week. I decided on this weekly schedule keeping in mind that the observation would be mentally demanding.

I also needed to allow time for travelling and time to record field notes on my computer at the University after each observation period. I left some days of the week free from observation in order to give time to think, read and reflect. For a novice researcher, these days were important to learn about the research process and understand what was going on. An understanding was developing throughout the data collection both in relation to the practical outworking of doing research as well as starting to think about what was coming out of my field work. Because I was committed to a certain understanding of the phenomenon 'being with' prior to the research as well as when doing the research it was both emotionally and intellectually demanding to work out what was going on and to be able to continue with a research that would both reflect my own understanding of the phenomenon but also the nurses/ncas' understanding. Hence, it was very important to have days not doing field work when I was able to engage with this task, reflect on my own assumptions and think about what I was observing.

When I was at the hospice I would ask to shadow a particular nurse/nursing care assistant, as he/she was caring for her patients, for the hours I was at the hospice each day. I kept this routine throughout the fieldwork. I did my fieldwork either in the mornings between 9 a.m. and 12 midday or in the afternoon from 2-6 p.m. The nurses/nursing care assistants told me that the period from 2-6 p.m. was usually less busy for them and hence I thought it might be important to observe the period when they were less busy as it might have implications in terms of seeing how the phenomenon 'being with' was constructed both during busy and less busy periods. I did not observe the nurses/nursing care assistants who did the night shifts from 8 p.m. to 8 a.m. Separate staff did night shifts by rotation. This may be a limitation of the study as there is a notion that night-time is when nurses/nursing care assistants have time and opportunity to do 'being with' in the way that I was expecting the phenomenon to be constructed. However, time did not seem to interfere with how the nurses/nursing care assistants did in fact construct the phenomenon 'being with'. For example I observed at times that were less busy in terms of tasks needing to be done, e.g. the time from 2-6 p.m., and I did not see 'being with' happen in any other way than during the busy morning hours.

After the first weeks of following the protocol (e.g. attending meetings, being monitored by the charge nurse and team leaders) in order to gain full access into the setting I was able to observe the nurses/nursing care assistants when interacting with patients. I had no resistance from the nurses/nursing care assistants. I found it easy to fit into the setting in terms of being accepted and not being noticed too much. For example, once when I was shadowing a nurse she said to me, "Oh sorry, I hardly noticed you, I am just carrying on as usual". This was of course exactly what I wanted them to do. It may be that being a palliative care nurse myself was an advantage in terms of the nurses/nursing care assistants trusting me around patients and observing what was happening because they knew I was knowledgeable about palliative care nursing. However it also meant that I had certain expectations of palliative care practice, although as noted this should not have influenced my observation of how the nurses/nursing care assistants did 'being with' as I was aiming to understand the participants' way of doing things. I was part of the setting in order to learn to interpret and experience events in the way they did (Emerson 1995 et al).

Participant observation seeks to uncover, make accessible, and reveal the meanings people use to make sense out of their daily lives (Jorgensen 1989 p. 15).

I had to constantly remind myself of this principle so that the fact that I am a palliative care nurse myself would not be a disadvantage for this study.

In order to be able to focus on the meaning of the phenomenon as created by the members without making reference to my own understanding, I had to manage my own preconception of the phenomenon. I did find it difficult sometimes to maintain objectivity and not assess what the nurses/nursing care assistants were doing based on my own understanding, that is, they were not 'being with' as I understood it. Because I was a palliative care nurse I sometimes found it difficult to collect data on what happened in the interaction between the nurses/nursing care assistants and their patients when the nurses/nursing care assistants did something other than I expected from my own preconception of the phenomenon. However I was guided by my knowledge of the importance of documenting field-notes that would represent the members' actions rather than my interpretation of the actions. I had to document just what I saw. I had to avoid any interpretation based on my own understanding. I knew

I had to aim to learn what was required to be a member of the setting and to experience events and meanings in a way that members were experiencing them (Emerson et al 1995). As I spent time in the setting I tried to understand the setting in the way the members saw it. When the nurses/nursing care assistants behaved differently from what I expected I would document that rather than try to interpret it. I would keep that for later when I would more formally start to interpret what was going on.

Example (1605) from jotted notes about my own experience

I feel so vulnerable around the patients when they are upset, I sometimes get tearful myself. I notice that the nurses/nursing care assistants do not seem to feel the same, they always appear strong and they don't show their feelings. I wonder why that is??.

I tried to understand them:

Example(3007) from jotted notes:

Every one looks tired, a thought goes through my head "It is hard to work here".

I tried to understand what they were doing and what the meaning was behind their actions:

Example(1705 from) jotted notes:

First [when I started the data collection and] I walked about in the hallway, the sight of patients lying in their beds made me think "This is a strange place". But now I see it differently, I see it more as comfortable, more normal... I can see how the staff are trying to keep things normal. The nursing care assistants are in a happy mood around the patients, it gives a feeling of "Everything is ok here", "This is a good place", "Everything is going to be fine".

I also tried to understand why they needed to behave in the way they did

Example (3010) from jotted notes:

A few members of staff are chatting together in the nursing office, they are all happy and jolly. Maybe they need to maintain their happy, cheery expression in order to manage the work.

Example (2008) from my field notes

I arrive at the hospice at 13:15. It is a beautiful day and the sun is shining, few nursing care assistants sit in a car smoking. One of them says to me "So you are back, it is busy now you should have been here this morning, we would have had plenty to do for you." I say "Oh well, maybe I should avoid the mornings then". There is laughter in the car and I laugh as well. I think to myself maybe I am too hard on them, it is a difficult job they are doing. They need their attitude to survive. Do they need a certain attitude to survive working at the hospice? When I enter into the hospice I smell a heavy smell, I think basically none of us want to be here. Maybe everyone is trying to cope by being nice to each other and joking.

I see the doctor. I say "Hi" to her cheerfully and she says "Hi" to me cheerfully. Maybe this is a way to cope after all. To hide the difficulty of being here by smiling and being nice. I have to admit greeting the doctor so cheerfully makes me feel a bit better about having to go into the hospice on this sunny day. .

This increased my sensitivity to the experience of being a member in the setting and helped me to understand them. I constantly reminded myself of the ethnomethodological principle that the study was about how the members understood the phenomenon as it appeared in the context of their day-to-day work, not my expectations of the phenomenon.

Throughout the data collection, I also forced myself to document as thoroughly and accurately as possible what I saw and leave any interpretation until later. I aimed at recording the situation as factually as possible- what was said and what was done- without interpreting it. I aimed towards letting my field notes show what happened rather than describe myself what happened by jotting down concrete details about actions and talk in a factual way. I also tried to avoid making statements that characterised what people did based on generalisation (Emerson et al 1995). I aimed towards making a verbatim record of what people said as far as possible. Emerson et al (1995) define this as descriptive, to take down notes that describe in detail what happened rather than summarise. Spradley (1980) points out how easy it is to translate what people have actually said when recording it as field-notes; he also points out how that might obscure the meaning of events to members. When I was around the nurses at meetings or in the hallway I would pay attention to what they said to each other and record that as accurately as I could.

Example (1110) from jotted notes:

Nurse at 14:30:" I need to do the notes- I have not done any notes-I am a bad nurse"

Example (0910) from jotted notes:

The meeting has started. The nurse tells the others at the meeting "We have lost Mr... Mrs... and Mr... and we have free beds".

When observing the interaction between the nurses/nursing care assistants and the patients I tried to document as thoroughly as I could what happened by describing remarks and actions.

Example (0606) from jotted notes:

The nursing care assistants and I help a patient out of the bed and to sit in a bath-chair. She tells me that he had an accident the other night so the night staff gave him a bath yesterday and he is very much looking forward to going into the bath now. When the nursing care assistant asks him to take a seat she says his name and lets it rhyme with sittingam. The patient laughs and when taking his urine-bag she says, "Here is your handbag". We wheel him into the bathroom and as we are doing that the nursing care assistants goes into the nursing office. When she comes back she says "I just wanted to see if I was first or second". We go into the bathroom and I ask her if she is first or second. She says second. When we are just starting to help the patient to undress another nursing care assistant comes into the bathroom and says, "I will help you, she needs to go for her tea. Then she says to the patient, "I will throw you into the bath".

There were lots of things happening in this encounter between the patient and the nursing care assistants. However I aimed towards documenting what happened and what was said, even though I found it strange and different from the way I would do it myself. Later, during the analysis of the data I would try to understand this encounter.

As Emerson (et al 1995) suggest I recorded dialogues between the nurses/nursing care assistants and the patients and also between the nurses/nursing care assistants.

Extract from jotted notes:

N1 Oh gosh it is a bunch we have

(every one smiles, looks at each other)

N2 Anything about the staff today?

N2 Oh it will be ok, I will muddle through

I had a small notebook in my pocket and I would retire to a quiet place such as an empty side room to write notes following the observation. On some occasions this was the toilet. I recorded key issues and as many of the direct quotes as I could. I tried to hold direct quotes in my head until I could write them down; often this was within a couple of minutes. I aimed to record as much of the actual language that was used and to be factual about what I saw.

I usually avoided letting the nurses/nursing care assistants see me writing down my observations, as I wanted them to forget that I was observing them. However as the observation period went on and they got used to me, I felt I could sometimes write notes in the nursing office. It was a normal sight to see the nurses sitting in the nursing office writing, and, in a sense, I fitted into that. Sometimes I would have a book or something by my side so it would look as though I was more interested in documenting theoretical knowledge rather than recording what I had seen them doing in the field. So if writing down my field notes in the nursing office felt naturally comfortable I would do so, as I found it important to try to write down as much as I could when actually in the field.

After my fieldwork I would usually take public transport to the University. Here I would type up the field-notes from the day into my computer. The transport took about half an hour and during this time I would look at what I had already jotted down. Often I would start to write more during the journey to the University when my memory was still fresh. All field-notes were written into my computer within a few hours of having done the fieldwork. Trying to document my observations as accurately as I could was labour-intensive and draining work. I knew this was crucial: to have field-notes that would represent the nurses/nursing care assistants' behaviour rather than my interpretation of the situation. I was passionate about this, as is evidenced by a note that I wrote down after talking to a senior research fellow about doing fieldwork. "No matter if you need to cut your own wrist with a razor blade, record your observation!" I took this advice seriously and became obsessed with recording. I realised that the fundamental issue to observational study is recording as Emerson et al (1995) point out.

At first glance, it might seem that the pursuit of members' meanings is fundamentally a matter not of writing but of what one does in the field of asking questions and positioning oneself to hear and observe others' concerns. Members' meanings, however, are not pristine objects that are simply "discovered". Rather, these meanings are interpretive constructions assembled and conveyed by the ethnographer. This process certainly begins with asking questions and paying attention to what is relevant to people in some indigenous group. But the key to the process lies in sensitively representing in written texts what local people consider meaningful and then making their concerns accessible to readers who are unfamiliar with their social world. Ultimately, members' concerns must be written down as fieldnotes and then incorporated into more comprehensive ethnographic accounts (Emerson et al 1995 p.108)

As well as writing verbatim field-notes I found it helpful to keep ethnographic questions in mind whilst in the field, like “What are they trying to accomplish? And how do they do this? What strategies do they use? How do members talk about and characterise and understand what is going on? What assumptions are they making? What do I see going on here? What am I learning about the members?” (Emerson et al 1995). These questions started when in the field and continued into formal analysis later on. I did not start formal analysis in the field but focused on recording what I observed within the framework I have described above. Hence formal analysis of data did not start until after the data collection was finished. I then examined the situation or text by continuing to ask the above questions and produce my own responses that I expanded in the data analysis and writing.

Interviews

As reported earlier in this chapter the nurses/ nursing care assistants’ actions in relation to the phenomenon ‘being with’ were at the heart of my investigation. I followed the ethnomethodological approach not to theorise about the phenomenon with my participants, but to see how they constructed the phenomenon with their actions. However as already discussed I did not only use ethnomethodology. I wanted to be more critical but at the same time understand the participants and try to encapsulate their background knowledge and the features that they were using in their day-to-day work. In order to increase my understanding of the participants, I included informal chats in the data collection. In an ethnographic approach to data collection the researcher also pays attention to what people say as this is seen as part of tacit knowledge (Spradley 1980). If the researcher has developed a friendly relationship with the participants, he/she may want to ask for an interview which can help to discover the cultural meaning they have learned (Spradley 1980).

In accordance with the underpinning philosophy of this research I was not expecting the nurses/ nursing care assistants to talk about ‘being with’ directly or explain in the interview how they constructed the phenomenon. However, I found a chat helpful in terms of trying to understand them, and at the same time answer some of the ethnographic questions stated above. Often this chat happened spontaneously when I was observing the nurses. For example, after I had been shadowing them they would

talk to me about the patient or comment on something that happened. Sometimes I would ask them questions in relation to their work. I found this gave me useful information about their own perception of their work. However as part of my exit out of the field during the last month of my data collecting I spent a lot of time informally chatting with the nurses/nursing care assistants. I tape-recorded these informal chats as I found that taking down notes could interrupt the natural flow of the conversation. In my analysis, I have not separated out data gathered through observation from data gathered from the informal chats.

In this informal setting I asked the nurses/nursing care assistants if they would be willing to sit down with me and have a chat. Consent was again given verbally. During this period I tape-recorded six conversations. Each informal chat was unstructured and I didn't prepare questions in advance. I started by reminding them about my interest in the phenomenon 'being with' and asked them if they could give me examples of 'being with'. All of them found that difficult.

Audrey Interview transcript 0312

I: Can you give me example of a situation that has happened recently that you would describe as 'being with'?

A: I am trying to think..... [laughs] Oh you just get stuck, Could you not maybe just ask me a question?

Alda Interview transcript 0212

I: As you know I have been observing 'being with' here...how would you describe 'being with' in your work... Can you give me an example?

Al: Right, right.

Al: Well I see 'being with' as part of my job as soon as I come in the door in the morning until when I go away.

It was not really the point of the interview to ask them to describe 'being with'. I used the discussion about 'being with' as a springboard for discussion about how they perceived their work as being around dying patients. I wanted to enhance my understanding of their actions in order to be able to answer the ethnographic questions. Any meaning of an action is often not directly expressed by language, but communicated indirectly through a description of the activity (Spradley 1980). The informal chats lasted from 30 minutes to one hour. They gave me insight into the meaning of 'being with' patients who were close to death from the nurses/nursing

care assistants' perspective. It was clear that their understanding of 'being with' was different from mine: for example, Alda says that she is 'being with' from the minute she enters the hospice until she leaves.

Audrey Interview transcript 0312:

I: There are a high number of deaths in here. There can be even 2-3 per week.

A: Aha, sometimes you can have six in two days, eight in two days. I mean, if you didn't switch off you would be... you wouldn't be anything, I think. I think you could not work here if you could not switch off. I think there must be a switch [laughs] switches off.

I: Someone would probably say "How can you work there? ... people are dying all the time"

A: Yes and they keep saying you are a special person if you do it, but I do not feel a special person, I just feel..... if I can help them. I do not feel special. I don't think I have got anything that anybody else hasn't got, but I just feel.... I feel satisfied if I can see them nice and happy and content and settled.

Audrey tells me how it is important for her to see patients in comfort, and she also thinks she can switch off to protect herself from an emotional response. This indicated that she protects herself from the experience of emotional pain by avoiding painful emotions rather than working through them.

As a part of my departure from the field I offered to give the staff at the hospice a short seminar to discuss my preliminary findings. This was important for me for two reasons: I wanted to be able to give something back to the participants who had so generously allowed me to shadow them, and I was also interested in their reaction. Even though the analysis was preliminary to any formal analysis, and was based on my thinking when still in the field, it did not change in any fundamental way after formal analysis. The nurses/nursing care assistants agreed that what I presented in this seminar did sound like an accurate description of their practice.

Understanding and transforming data

As stated earlier in this chapter, I followed Garfinkel's principle of not having a preconception of the phenomenon when I started the data collection since I wanted to focus on how the nurses/nursing care assistants constructed it. I also followed Taylor's principle of understanding the participants even though I did not have an

‘empathic understanding’ of what they were doing. By constantly thinking ‘What are they trying to do?’, ‘What are they trying to achieve?’, ‘What are their intentions?’ I aimed to understand the nurses/nursing care assistants. In asking questions the researcher draws on a wide variety of resources, including sensitivity towards the concerns and orientation of members (Emerson et al 1995). When in the field, I paid attention to the whole context of the nurses/nursing care assistants’ work and through this I started to understand them. This understanding developed as themes. Through carefully observing the participants’ actions and the context of their actions, I started to see certain threads that I thought were vital for the way the phenomenon ‘being with’ was understood in the field. I noticed behaviours and attitudes that I considered important in this respect. For example, the nurses/nursing care assistants were always very cheerful and chatty when around the patients, they showed gentleness and kindness, and they also appeared very busy. Hence, very early on in the data collection I followed a hunch that I considered important in relation to how the participants understood the phenomenon. This hunch was what actually drove my research and helped to focus it. Later on, during my formal analysis themes developed based on this hunch (Jorgensen 1989, Holliday 2002). Taylor’s approach to analysis places itself close to understanding texts in the same way as the hermeneutic method in that ‘emerging themes’ come out of reading and rereading a text in order to understand participants. These emerging themes which developed through the analysis were fundamental to further analysis in terms of representing the dialogue between myself and the data (Jorgensen 1989, Holliday 2002). They focused the analysis and formed the storyline that grew out of the data (Holliday 2002, Wolcott 1994). Early impressions and hunches helped to make sense of the data, and to form, adjust and reform the argument and structure of the thesis (Holliday 2002).

Neither Garfinkel nor Taylor offer a method for the interpretation of text. Their philosophy underpinned the way I went about collecting the data. It also informed the choice of ethnographic questions I asked when in the field. Through this, data collection was focused and made rigorous. I found no prescribed way of interpreting the text in their work.

What I found helpful was Holliday's (2002) structure of identifying and using themes in order to develop the argument of a thesis¹⁷. She suggests that the first step in formal analysis is to look at the overall character of the body of the data, and in doing so to search for natural divisions in the data. This she claims is informed by hunches and focuses on areas of significance that arise during data collection as well as patterns that arise during formal data analysis. In the field I had already started to form themes and when reading the data further I analysed it according to these themes.

As described earlier, I jotted notes down during the observation in the field, and then after each observation I wrote up at my desk further field notes for that day. Each of the six informal chats were transcribed verbatim. This formed the text for data analysis. Early impressions and hunches helped me to divide the data naturally into three chapters. What I also found helpful during my formal analysis of the data was to follow Wolcott's (1994) advice on transforming qualitative data. What he advises is that a novice researcher in particular should avoid starting to interpret data too soon and try to stay as close to the data as possible, 'to let the data speak'.

One way of doing something with data in rendering an account is to stay close to the data as originally recorded. The final account may draw long excerpts from one's field-notes, or repeat informants' words so that informants themselves seem to tell their stories. The strategy of this approach is to treat descriptive data as facts. The underlying assumption, or hope, is that the data "speak for themselves". (Wolcott 1994 p. 10)

This advice I found helpful especially in terms of encouraging me to work at trying to understand the participants. It helped me to understand them and hold back my own understanding of the phenomenon. I followed Wolcott's (1994) advice and read through my field-notes with the aim of 'letting the data speak' and not interpreting what was happening. I read through the observation and the informal chats with this principle in mind. Hence the three chapters that my data formed in the beginning were aimed at telling the story through the data. They were a descriptive account of my data informed by early hunches in the field.

This was helpful in terms of managing the large amount of data that I had from the data collection. To have the data in these three chapters made it more manageable to

¹⁷ For those interested in further detail see chapter five in Holliday (2002).

deal with further analysis. Following Wolcott's (1994) and Holliday's (2002) approach to data analysis I first of all transformed recorded field-notes into a descriptive account that presented what was happening. By doing this some interpretation had already started, as I was aware that whatever I included in the descriptive account needed to be assessed on its relevance and contribution to the story being developed (Wolcott 1994). However, I avoided interpreting what was happening and aimed at presenting it in a factual way.

Holliday (2002) suggests that the next step in data analysis is to determine the character of each division and find a heading that suits each division. The headings then help to make further sense of the data so as to organise the writing. By following these steps an argument develops. Hence, I read through the descriptive account with more interpretative focus than before. Through interpretation of data an argument evolves and the focus becomes narrower. I followed Wolcott's (1994 p. 14) advice when deciding what would be included in the story: 'Every detail considered for inclusion must be subject to a critical judgement'. In deciding on the level of detail I considered that what would be included had to be relevant and appropriate for the argument to add up (Wolcott 1994). At this point I had started to develop an argument for this thesis.

The next step in my analysis was that I re-read and rewrote the chapters. According to Wolcott (1994), interpretation is asking the questions 'What does this mean?', 'What do I make of this?' I read each descriptive chapter over again and asked myself, 'What am I learning about the way members construct the phenomenon?' This happened through continuously reading the descriptive chapters and by thinking about them, writing and rewriting. Through this process, the account matured in the way it is presented in this study. I reworked the chapters and gave each chapter headings and subheadings that represented what was going on. For example, the first analytical chapter was named 'Physical care is the main focus of care'; the subheadings were, for example 'The staff are busy trying to provide care to every patient' 'The physical care is provided in a certain way', and 'Groups of nurses/nursing care assistants take care of groups of patients'. The second chapter had the heading 'The relationship between the patients and the nurses/nursing care assistants is based on "doing for"' with subheadings like 'The nurse/nursing care assistant knows what to do' and "The

patients are dependent on the nurses/nursing care assistants'. The third chapter had the heading 'Death is organised and seen as the end goal'. The end results of this analysis are presented in chapters four, five, six and seven. Through the analysis I changed the headings as I considered and interpreted what was going on and also added one further chapter.

The way the data chapters are written corresponds to how the analysis of the data enlightened my understanding of the nurses/nursing care assistants' perception of the phenomenon. The first analytical chapter (chapter four) developed from the first descriptive draft and I aimed at keeping it as descriptive as possible to give the reader insight into the day-to-day work of the nurses/nursing care assistants in the hospice which would enhance understanding later on. I considered it important to have such a starting point in order to enhance understanding of the nurses/ncas. While chapter four deals with what goes on in the nurses' day-to-day work in a factual way, in chapter five I aimed at describing what this meant. Hence the meaning and outcome of the nursing care is the focus of the second analytical chapter. In chapter six I allow my own understanding of the phenomenon 'being with' to come into play and show how the nurses' actions are not oriented towards 'being with' as I understand the phenomenon. Chapter seven deals with how the nurses/nursing care assistants managed death. Early on in the data collection I considered this to be important in understanding (how the phenomenon 'being with' happens in the field). This study then finally leads to chapter eight explaining what was going on by revisiting Cicely Saunders' notion of 'being with' and Heidegger's theory of how human beings face death in.

It is the understanding gained through this analytical process that this thesis now turns to.

Chapter Four

The ordinary work of nursing dying patients

Introduction

This chapter, which is the first of four in which I will present my data, will introduce the context in which the nurses/ncas worked, that is, the physical location of the hospice setting and its layout. The main content of this chapter describes the nurses'/ncas' ordinary day-to-day work. It shows how the nurses/ncas structured the care of dying patients. In order ensure confidentiality all names are pseudonyms. Pseudonyms for care assistants will all start with A to identify them as nursing care assistants, pseudonyms for nurses will all start with N to identify them as nurses, and the pseudonym for a nursing student is Sarah. The pseudonyms for patients will all start with P to identify them as patients. On occasions where doctors are mentioned the pseudonym for them will start with D.

The setting, M Hospice

M Hospice is situated in one of Scotland's cities in a quiet and pleasant setting. The building is accessed from a mainroad and a mile-long driveway leads to an attractive light sandstone building surrounded by trees. These features and an expansive lawn give the place a feeling of peace. A parking area providing space for limited number of cars lies behind the hospice building. When going through the main entrance one comes first to the reception desk occupied by volunteers. The volunteers answer phone calls coming into the hospice and any enquiries from visitors. Turning right leads to the day care centre and turning left leads to one of the in-patient wards. M Hospice consists of two in-patient wards, a day care unit and a home care unit. I did my observation exclusively in the in-patient wards.

Geographically the in-patient wards are based on two floors, one on the ground floor and one on the first floor. The ward on the ground floor has beds for 18 patients, two one-bedded and four four-bedded. The first floor has beds for 19 patients, and also four rooms which are four-bedded but also three single rooms. The layout is very similar in both wards. The patients' rooms lead off the same side of a main corridor and on other side are rooms needed in relation to the care such as the nursing station, sluice, drugs room and storage room. Both wards have big cupboards in the middle of the corridor where clean sheets for the patients' beds are kept. Both the wards have a specific sitting area for the patients. The ground floor has as its sitting area a conservatory running along the whole of the corridor, which is bright and decorated with flowers and is accessible from each of the patients' rooms. The first floor has its sitting room at the end of the corridor. During the period of my observation a few beds were closed due to lack of nurses and often there were 10-12 patients on each ward. In accordance with the hospice philosophy of care, as described in chapter two, the hospice mission was to provide palliative care organised through multidisciplinary teamwork in order to manage the symptoms the disease might be causing the patients. The setting had in the past been a nursing home (established as such in 1966) prior to becoming a hospice setting. However for at least 10 years it has been running as a hospice organisation.

The patients at M Hospice

When I collected data at the hospice, it was admitting patients with advanced incurable diseases, mostly cancer patients. The patients at the hospice had all reached a stage where it had become clear that it was not possible to cure the disease they had, since it was progressing and the treatment that they had been undertaking at a hospital in the past for curative purposes had not been successful. The patient would have been told at some point about their prognosis, since, as noted earlier in this thesis, within the hospice philosophy it is common practice that this is made explicit. However when and how this was made explicit to the patient did not become clear to me whilst doing the study. However it was noticeable that the staff expected the patients and the family to know. For example in a discussion between the nurse and the doctor about

the patient's poor prognosis, the doctor asked the nurse 'Do they know?' (Referring to the patient and his/her family) and the nurse said 'Yes they do know' (1606).

It is primarily the nursing care which is the focus of this study, and early on in my data collection it became evident to me that the patients at the hospice were highly dependent on help from the nurses/ncas¹⁸ in relation to personal care. As I observed the nurses/ncas I realised that I had taken this for granted in my own practice as a palliative care nurse and it was only through the observation that I started to notice what a big part of the nursing care this was.¹⁹ The patients needed assistance with what people in day-to-day normal life can do for themselves without any help such as eating, dressing, bathing, and going to the toilet. Some of the patients also had unpleasant symptoms such as large cancer wounds with a distasteful smell. Also, many of the patients had lost control of their bodily functions and they needed care that Lawer (1991) has described as 'dirty'. Furthermore, they also relied on the nurses in addition to other health care professionals at the hospice to manage the symptoms of the disease such as pain or nausea.

As well as the patients knowing about the seriousness of their condition, the nurses/ncas and other health care professionals working at the hospice also knew that none of the patients at the hospice would recover from their disease. They might expect that some would recover from the symptoms of the disease but only temporarily. It might be possible to improve the situation for a while and the patient might be discharged from the hospice, but he/she would come into the hospice again and eventually die there or at home. Patients were usually at the hospice for a short time, and would not be admitted to the hospice for long term stay. The average length of stay in 2002 was 13 days. However, the same patients might come into the hospice a few times. If a patient was not very close to death but could not go home, he/she was most often transferred to a nursing home.

¹⁸ From now on the nursing care assistants will be referred to as 'ncas' except when I am referring to a specific nursing care assistant.

The nurses and nursing care assistants at M Hospice

On the first floor ten nurses and five ncas were employed and on the ground floor seven nurses and six ncas. The nurses are classified as D, E, F, or G grade depending on their qualifications and work experience, D being the least experienced and qualified. Some of the nurses/ncas were working part-time, others full-time. The nurses/ncas would be employed on one of the wards and they would not rotate between the wards. However on a few occasions I noted that a nurse had been 'borrowed' from the ward she was employed on by another ward because of staff shortage. Most of the nursing care assistants had been working at the hospice for over five years and some of them over twenty years, which meant that they had been working within the setting when it was a nursing home establishment. On each ward there was an F grade nurse who was the team leader and was in charge of the nursing care on the ward. The nurses and nursing care assistants at the hospice were mainly responsible for providing the day-to-day care for the patients but there were also three social workers, one chaplain, an occupational therapist, a physiotherapist, a pharmacist, and three doctors.

In this thesis I am focusing on the nursing care within the hospice which is only one aspect of the overall care provided. The multidisciplinary team met once a week to plan and organise the overall care of the patients. However, since the nursing care was the focus of the study, data regarding the care provided by members of the multidisciplinary team other than nurses and nursing care assistants was not collected.

Structuring the nursing care at M Hospice

The hospice offered 24-hour nursing care for the patients, and the nurses and nursing care assistants worked in shift patterns in order to manage the day-to-day care. The 24 hours were broken up into 3 shifts: early shift started at 7:45 and finished at 15:45, back-shift started at 1 and finished at 9, and night shift started at 8 in the evening and

¹⁹ Lawer (1991) provides an excellent account in her study of the work of providing physical nursing care which is taken for granted.

finished at 8 in the morning. Because of the way the shifts were organised there was an overlap of staff between 13 and 15:45 in the afternoon. There were usually about five to seven nurses/ncas on each ward on early shifts, four to five on back shift and three on night shifts. During the fieldwork, I observed the nurses/ncas when they were on early and on back-shift. I noted that activities during the shift were scheduled around the clock, and the same things were done at the same time every day. I noted that this created an atmosphere of 'busyness' in the mornings and 'quietness' in the afternoon, as will be discussed later in the chapter. The way the nurses/ncas organised their work was through teamwork and tape report.

Teamwork

Each day there could be 2-3 nurses/ncas working in a team taking care of 4-6 patients. The nurses/ncas organised their care for the patient during the shifts by working in teams and were divided into two groups: the red and green team. Nurses/ncas in the red team always worked together and the same applied to the green team. There was always at least one nurse in the team for each shift. When the nurses/ncas arrived on their shift they could read their names written on a white board in the nursing office that showed which members of the nursing team were on duty that day. The names of patients on the ward were also written out on the white board and the nurses/ncas could see which patients had been allocated to the team that day. Teamwork is a common way of organising day-to-day nursing care and I could see how this was convenient in relation to sharing the burden of caring for dying patients. However what became evident to me when doing the fieldwork was that this could also be an obstacle in relation to creating the opportunity for 'being with' in facing death to happen. This will be discussed further in chapter eight and nine.

Tape report

At the beginning of each shift the nurses/ncas would listen to a tape report from the nurse on the previous shift. The nurse who recorded the tape spoke about the patients in terms of what symptoms they had. If a patient had not been long in the hospice and

was not known by all the nurses/ncas who were listening to the tape, he/she would be described in terms of age, the disease he/she had and the symptoms the disease were causing him/her. If the patients had been at the hospice for a longer time (such as over a week) he would only be described in terms of symptoms.

(3009) I listen to the tape report with the nurses/ncas, who have recently started their shift. Nita speaks on the tape and she gives us information about the patients that are in the hospice now. Peggy is 69 years old; she has carcinoma and metastasis, she is in for pain control, she has back pain and is on diamorphine , independent. Patricia is 64 years old; she had mesothelium cancer diagnosed 6-7 weeks ago and COPD, she is immobile, anxious, and has anxiety over pain. Paul has pain, is anxious, tearful and confused.

I noted that after the nurses/ncas had listened to the tape report they would have a better sense of who the patients were and what they needed to do for them in terms of nursing care. I noted that this seemed to help the nurses/ncas to structure their work and gave them a sense of what they could expect to happen during their shift. For example, once when I asked a nurse who had just arrived on the backshift if I could follow her during the first half of her shift, she looked at me anxiously and said ‘No, I don’t know the patients’. Once we had listened to the tape report she looked much more relaxed and said to me with confidence in her voice ‘I do know some of the patients so you can follow me’. It may well be that arriving on a shift knowing that one was responsible for looking after a number of dying patients was a bit overwhelming. Once the nurse knew what patients she was looking after and what were the main needs she was meant to attend to, she felt better and more secure. If some of the patients were not new to her it may have eased her anxiety; she had nursed them before and she knew what to expect. This indicates that the nurses reduced their anxiety through knowing what was expected of them, which might have given them sense of a control, if they knew they could handle the situation. However this approach to the care in fact conflicts with the idea and opportunity for ‘being with’, as discussed in chapter two. ‘Being with’ in facing death includes not knowing the answers and exploring the unknown which may create sense of insecurity. This will be discussed further in chapters eight and nine.

The tape report helped the nurses/ncas to know what to expect and throughout their shift the nurses/ncas would attend to patients based on this information; it helped to structure their work. One way this was done was that the tape report indicated what the nurses/ncas should or should not attend to in relation to the patients' care. For example, once when I was listening to the tape report, the nurse reading on the tape remarked on one of the patients, 'Her husband is difficult but we are not going to be involved'(3009). This indicated that as a group the nurses would decide what appropriate involvement with the patients and their families was. The care was structured by the tape report and indicated what suitable care was. Each patient had been categorised by what his/her needs were in relation to the symptoms of his/her disease, it had been collectively agreed what these were, and this focused the nurses/ncas' care. The main focus of the information offered on the tape report was around the effect terminal illness had on the patient and how much he/she was dependent on the nurses/ncas help in order to maintain comfort. The patients were classified based on how frail they were, from being independent (which only very few patients were) to being totally bed-bound. This would also indicate to what extent the patient needed assistance with personal hygiene.

The mornings at M Hospice

For the first weeks of doing fieldwork I observed the nurses/ncas between 9a.m. and 12 midday. I usually arrived at the hospice between 8:30 and 9a.m. The nurses/ncas arrived at 7:45 a.m. and started their shift by listening to the tape report from the night duty nurse. They then helped the patients with breakfast; having their breakfast, some of them needed assistance and some even needed to be spoon-fed. When I arrived breakfast was usually over and the nurses/ncas were helping the patients with their personal hygiene. Every patient needed an assistant to some degree. Some patients were well enough to be up and about and to get dressed and sit in a chair either in their room or in the sitting room after they had been helped to bathe/wash. Other patients were more ill and closer to death and they were in their beds, some of them unconscious. For the nurses and nursing care assistants at the hospice the time between 9 and 11 was dedicated to helping the patients with physical care. I noted

how this focused the nurses/ncas' attention around helping all the patients with personal hygiene during this time.

General busyness

When I arrived in the mornings it was very apparent that the nurses/ncas were occupied and busy with helping the patients to wash or have a bath. Usually I would see them moving about in the hallway with their white plastic aprons over their uniform, and they all looked busy and occupied. For example, one morning when I arrived I could see that Alda was looking for something in the big cupboard where clean linen was stored and she was holding a bucket. Amy was going into a patient's room with clean bed sheets and Andrea was pushing a patient in a wheelchair to the bathroom (2705). It seemed that everyone was occupied and focused on what they were doing, and the atmosphere felt busy. If I had not made a request the day before regarding which nurse/nca I could follow that day, I sometimes wandered about a bit before I found someone that I felt I could ask. Wandering about I felt out of place but I also hesitated to approach them because they all looked so busy (for more details on my observation method, see chapter three).

I noted that the nurses/ncas did not try to downplay the busyness; it was obvious by the way they moved about in the hallway and also by what they said. For example, once I was in the sitting room where there were two patients called Paul and Patrick. Audrey was sitting in front of Patrick and she was starting to shave him when Nora came into the room. Audrey said to Nora, 'Oh I need to shave Patrick and Paul is sitting here and also needs.. oh' (2705). Sometimes I felt that they were exaggerating how busy they were by moving about more than necessary when they were attending to a patient.

(2005) Audrey is helping Petra to wash. Someone comes in to tell Audrey there is a phone call for her. She stops washing Petra and asks me to stay with her. Another time she goes out of the room again to answer the phone, which is ringing in the hallway. She says "I need to go and get it" but then it stops ringing and she says, "Oh someone else has got it". A few times she goes out of the room to get something needed for washing Petra but which she has forgotten. Once she picks up a file (a patient's medical and nursing notes) lying in the next empty bed. When she notices the file she picks it up and says "This is Nancy's" (Nancy is the staff nurse working with her in the team). Audrey takes it to the nursing office

(where the files are usually kept). When she comes back she says with a happy and proud voice, "You see we can be very busy".

When observing at the hospice it appeared to me that the nurses/ncas liked to be busy. For example, once I asked a nurse 'Are you busy today?' She answered, 'Yes but that is good, it keeps us on the track' (1111). It was as if that was the right way to go about their work, as if they were 'on a roll'. Their shift had set tasks to do and a certain speed was required in order to get things done. The patient allocation, teamwork and the tape report created a schedule for their work that everyone was supposed to follow. The nurses/ncas were not expected to take any sideways turns, which would distort the routine of their work. There were jobs that needed to be done and everyone worked together in order to achieve that. For example, once I heard that a nurse was not happy about what she saw as a lack of achievement by a nursing student, Sarah, who had a placement on the ward. I had noticed that the nursing student did behave in a different way from the nurses/ncas. She seemed less rushed and did not move about as fast as the other nurses, and she was quieter.

(1006) Nita and Nellie are in the nursing office, a new patient has arrived and Nita asks Nellie if they have done the admission. Nellie says "No" and Nita says "No I did not expect that Sarah had done it". Nellie says "No I am not sure what it is: Maybe she needs to learn that we don't live in an ideal world".

For the nurses/ncas this was the 'real world', and there were lots of things that needed to be done for the patients. In order to achieve that the nurses/ncas moved on a 'track' which had a certain pace that everyone was expected to keep up with.

I noted that the patients recognised the busyness displayed by the nurses/ncas with their many tasks. They became aware that the nurses/ncas were very busy trying to help everyone.

(1906) Noreen tells Paula that she must to let them know immediately if she has pain because it is much better to get rid of the pain then. Paula says "But you are so busy, I feel so guilty doing that".

Paula knows that the staff are busy and therefore she finds it difficult to ask them for something that increases the demands on them. It may be that the patients felt that they needed to comply with this busy routine. They could see the nurses and ncas were busy trying to help everyone with their physical care. They may have been

grateful for what the nurses/ncas were offering them, i.e. help with physical care, which most of them were in great need of and they knew this was the time when the nurses/ncas were busy trying to help every patient. For example, once when a nurse was helping Paul out of the bath he asked, "Who is next? Peter?" and the nurse, said "Yes". On another occasion a patient told me that he was waiting for a bath. When the nurse who was in the room heard this she said, "It is popular today, you are next in the queue". (2305,0406)

The nurses/ncas moved from one patient to another and helped them with personal hygiene. They attended to the patient that they had been allocated according to the white board and offered them help with either washing or having a bath. They always attended to them in a kind and friendly manner although their busyness was obvious as there were so many patients that they needed to attend to. For example, if the patient was not ready to have a bath/wash when they attended to him/her they went to another patient to see if he/she was ready.

(1006) Nellie goes into Peggy's room with a clean towel. Peggy is sitting in a chair beside her bed, and has just had her nebuliser. She tells Nellie that she is not ready to have her wash now. Nellie says to her "Just take your time" and puts a clean folded towel on her bed and makes things ready for the wash. She then leaves the room. On our way out of the room Nellie explains to me that Peggy has angina and needs to do things very slowly. She is going to sit for a bit in the chair before she gets help with the wash. Nellie goes into Paula's room. Paula hears badly and can not hear what Nellie is saying. Nellie writes on a paper asking her if she wants a bath or a wash? Paula says she is too frail to have a bath. Nellie agrees with this and starts to prepare things in order to help Paula to have a wash in her bed.

It was made obvious by the nurses/ncas' behaviour that the availability of the nurse/ncas to the patient was in relation to providing physical care, and that if that was not needed or the time not convenient for the patient the nurse would turn to another patient.

'Doing' the patients

The nurses and ncas called this activity of attending to the personal hygiene of patients 'doing the patients'. I could hear them checking with each other: 'Has Paula been done?', 'Do you want me to do Peter?' And, when it got closer to 11 o'clock,

'Has everyone been done?', 'Yes, we are done' (2205, 3005 1906). The nursing team worked together but each team also helped the other team out when it was seen as necessary. For example, if one team had finished 'doing' all their patients before 11 o'clock they would help the other team with their patients. Everyone at the hospice became aware that the time between 9 and 11 a.m. was dedicated to physical care and helping every patient with personal hygiene. The atmosphere was coloured by this fact and there was a 'doing mood' at the hospice at this time. It was a 'doing' time, the nurses/ncas were all preoccupied with helping the patients with their physical needs and everyone was expected to take part in that. They moved between patients and helped them. For example, when I saw a nurse sitting and talking to a patient during this time, she made excuses for that to the other members in her team.

(1710) Natalie is sitting on Prue's bed talking to her. Prue is talking about her family. At one point Natalie sees Audrey in the hallway. She is taking a sheet out of the hall cupboard. Natalie calls to her "What are you doing"? Audrey says, "Just getting on with things and helping Patricia". Natalie says "Patricia was asleep and Peter had not made up his mind so I am not skiving in case you think that". Audrey does not say anything. Natalie says "sorry" to Prue who carries on speaking.

To sit and talk to the patients did not seem to be acceptable in the mornings as there were tasks to attend to and these were prioritised by all nurses/ncas on the shift.

Distracted Attention

What I have described here is that there was a certain 'busy mood' around the hospice in the mornings which all nurses/ncas were expected to take part in. I also noted that whilst the nurses/ncas were busy focusing on providing physical care to the patients they did not have uninterrupted time to spend with each patient during this process. When helping the patients with personal hygiene, their attention to caring for a patient could be distracted by various things. For example, when a nca was helping a patient to have a bath, someone came into the room and asked her to attend to another patient whose nose was bleeding. Scheduled meetings the nurses were meant to attend could also cause this interruption for them. One of these was the 'doctors' meeting' around nine o'clock. The nurses would start attending to the physical care of the patients when the patients had finished breakfast around 8:30 a.m. but they would stop around

9a.m. to attend the doctors' meeting. A nca in the nurse team would take over from the nurse if she was in the middle of attending to a patient around nine. At 'the doctors' meeting', which usually lasted about half an hour, the doctors and nurses discussed the patient's care. They usually focused on how well symptoms were managed and on the patient's 'plan' i.e. whether he/she was staying at the hospice or going home and how close to death the patient was. This often took the form of the nurse informing the ward doctor what state the patient was in, what the plan was and if any symptoms were not being well managed. The doctor would suggest how to deal with the symptoms and this was discussed between the doctor and the nurse and sometimes would be acted on by one or both of them. The ncas did not attend this meeting.

Attending to helping the patients with personal hygiene was also interrupted by the nurses/ncas' coffee break. Around 9 o'clock they had a set time for their own break. They went for the break in two groups. The first group went about 9 a.m. and then the second group around 9:30 a.m. It was decided early in the morning and written on the white board in the nursing office which group was to go first and which second. The nurses/ncas left for a coffee break at their allocated time, rather than when they had a natural break between patients. This meant that they could be in middle of attending to a patient and helping him/her with washing or a bath when it was time for them to go for the break. When it was time for the first group to go for a coffee break the nurses/ncas in the later group would take over the care of a patient from the ones that were to go for a coffee break.

Nadia goes into Petra's room. There are 2 members of staff helping her to have a wash in her bed. Nadia asks if she can take over because they are meant to have a coffee break. One of them says "Oh am I in the first?" and Nadia says "yes". They leave and she takes over the washing.

The patients were aware that the staff broke up their work in the morning in this way; it was part of the whole morning routine and ensured that every nurse/nca could have her/his break. The patients knew that another nurse/nca might come to finish what one nurse/nca had started to help him/her with. For example, once when a nursing care assistant entered a patient's room and said to the nurse who was helping the patient with a wash 'Do you want me to take over?' 'Do you want to go for your cuppa?' the

patient said to her, 'Have you had your cuppa?' (2105). Even though someone else would usually take over the care, this could mean that the patient would wait for the nurse to come back from the coffee break to finish helping her, as when I was observing Noreen. She helped a patient to wash and put on a new night-dress before she had her coffee break and after she came back she helped the patient to brush her teeth, and changed her bed (1906).

I noted that in addition to taking part in providing physical care for the patients with the ncas, the nurses were responsible for assessing and managing the physical symptoms of the patients' illnesses. During the morning the nurses would often be called away from what they were doing, when they were assisting a patient with personal hygiene, because they had to attend to another patient suffering from a symptom of disease such as pain. If a patient was in pain, the nurse in the team that was looking after that patient had to assess the pain, check what drugs were prescribed for the pain by the doctors in the patient notes and give the appropriate drug to the patient. A bit later they would also assess if the drug had been effective for pain relief. If not, they would give another dose of medication and/or speak to the doctor and reassess with him/her what treatment might be appropriate. This would also be the case for other physical symptoms that the disease could cause the patients, such as nausea or confusion.

I noted that when the nurses were going around providing physical care their focus was on assessing the patients as if they were sometimes 'keeping an eye on them'. This also meant that the nurses/ncas would not only be focusing on the patient they were assisting with personal hygiene but also other patients because they were assessing their state. For example, when a nurse in a four-bedded room was helping a patient with personal hygiene she noticed that the patient in the next bed was not as alert as usual. She asked the patient, 'Are you sleepy today, a bit confused?' The patient answered, 'Yes I don't know what it is'. Later in the nursing office the nurse said to me, 'Peggy is definitely a bit confused and we need to watch her'. She told me that they had just changed from syringe driver to oral medication (1906). She was assessing the effect of this change and whether it was harming the patient. On another occasion I heard a nurse say to a colleague that she had put a sedative drug into one patient's syringe driver and commented, 'He is getting high again' (1006). The nurses

would do this assessment of their patients as they were moving about and attending to patients and assisting them with personal care in the mornings. This could also apply to family members as when I was observing the team leader of the ward making a patient's bed and she suddenly rushed out of the room. When she came back she said to me 'Sorry, I just saw [Paul's wife] and wanted to see how she is' (0411). Paul had died earlier that morning. Hence the nurses/ncas were not 'tuned in' to one patient at a time, but were conscious of the group of patients they were looking after. I would suggest that this denied them the opportunity to show during the personal care that they were available to him/her for a period of time. Consequently it is unlikely that the patient would bring up sensitive issues around death and dying knowing that the nurse/ncas might go away at any moment. This will be discussed further in chapter eight and nine.

The team leader at the ward (an F grade nurse), with the highest qualification and experience, had overall responsibility for the nursing care at the ward. There was one on each ward and they could have various responsibilities during the morning, both taking a direct part in the care of the patients in relation to their personal hygiene and assessing their patients' state and the need for intervention to manage discomfort. In addition they were expected to take part in meetings that would facilitate the patient care. I have already mentioned the doctors' meeting that took place every morning but they would also have to attend the planning meeting that was held every day except Thursday.

(3004) This is the planning meeting. Noreen tells me, where we focus on what new patients are possibly coming in, what patients are going home and what patients have died. It is a short meeting but is so important so we can start to expect people in the hospice so patients do not just appear at the door. We can start to plan and expect the potential patient coming in.

This meeting was scheduled just before nine and usually lasted only for 10-15 minutes. The charge nurse, the doctors, the nursing team leader from each ward, nurses from the Home Care Unit and a nurse from the Day Care Unit all attended this meeting. Hence one of the responsibilities of the F grade nurse was to have an overview of what was happening that enabled them to prepare the care, as well as give information to other senior members of the hospice about the patients on their ward.

This meant that the F grade nurse would be attending to various different things during the morning. For example, one morning when I observed the F grade nurse, Nora, I noted that between 9 and 10:30a.m., a period of an hour and a half, she had attended two meetings, the planning meeting and the doctors' meeting, and had helped two patients with personal hygiene. When she had finished that, someone told her that one of the patients was going home during the day and she went to fill the patient's syringe driver and organized and gave her medicine to take home with her. After that Nora went to check the oxygen supplies at the hospice because the janitor told her that he was concerned that they were low, and she noted that she needed to make an order for that. When she came into the nursing station a nursing care assistant asked her about a new patient who was coming in and what kind of bed the patient would need. She could tell her that because she had attended the planning meeting earlier that morning and knew what patient was coming in and what her needs were in relation to this. Then the doctor arrived in the nursing station and spoke to Nora about a patient that he had been seeing, and he reckoned this patient needed a higher dose of pain relief in her syringe driver. Nora found this patient's notes and together she and the doctor checked what dose the patient was on and the doctor wrote a prescription for the new dose which Nora would put into the syringe in about an hour when it would be changed. Someone told her that one patient was in pain and she went to attend to that patient, assess his pain, check what was prescribed for him and give him his medicine (1510).

It might be thought that the F grade nurse who was the most experienced and knowledgeable about palliative care would be the one most likely to do 'being with' as suggested by Saunders and described in chapter two. However with so many things to attend to, it is unlikely she would be able to. Furthermore, given that she is in charge of the nursing care, the F grade nurse might well be seen as a role model of care. With her being very busy attending to many things, the other nurses/ncas were maybe not encouraged to do 'being with' in the way it is described in chapter two.

I have shown how the way patient care in the morning was focused around physical care did not provide uninterrupted time for the nurse/ncas and the patients. When providing the physical care the nurses/ncas did not have designated time with a patient that was protected from interruption. This may have had implications for

'being with' in the way Saunders understood it (as shown in chapter two) in relation to showing availability for 'being with' to happen. I once observed a nurse twice leaving the patient she was helping with personal hygiene because she was asked to attend to two different patients who needed to be assessed regarding pain and needed intervention for the pain. The phone could also interrupt the nurse/ncas when helping a patient with personal care. For example, on one occasion a nursing care assistant was called away for a personal phone call and on more than one occasion I saw a nurse/ncas rush out of a patient's room to answer a phone that was ringing in the hallway. Sometimes a nurse was interrupted because she needed to know what had happened to the other patients on the ward.

(1510) Nora is giving Petra a wash in her bed, working behind the curtains. Nancy pops her head between the curtains and says, "Did you know Patricia's glasses are broken and she is a bit upset?" Nora says, "Yes we need to phone the optician and see if we can sort it out". Nancy goes away and Nora says to Petra "Sorry about this". At another point someone asks Nora where something is and Nora tells the person where she can find the missing article.

As I will discuss later in this thesis one of the senior nurses told me that the nurses/ncas would do 'being with' at the same time as providing the physical care. However, due to the way the physical care was organised, with no protected time for this to happen without interruption, it may be suggested that an opportunity for discussion around difficult matters such as death and dying was not facilitated. This will be further discussed in chapters eight and nine.

The effort of caring for dying patients

Physical effort

When doing the field work I noted that taking care of the body of another person involves physical effort due to the physical weakness of the patients, and that much effort was involved in helping them with the routine tasks regarding personal hygiene which healthy people can normally do for themselves. I had taken this for granted and did not notice it until observing the nurses/ncas' work closely. I started to pay attention to the nurses/ncas' attempts to help the patients to stand up, since due to

weakness many of the patients at the hospice could not stand up without help. Some of them could not stay upright without help and might even need two people to assist them in doing so. When wanting to sit up most of them needed assistance and some patients were totally bed-bound and could not move at all, in which case they needed to be turned in the bed to prevent pressure sores and discomfort. I noted how assisting the patient with personal hygiene and ensuring his/her comfort despite his/her disability could involve quite a lot of practical hands-on activity and physical effort from the nurse/ncas. On one occasion when I came into a room where a nursing care assistant had just finished helping a patient with a bed-bath, she was helping him to get dressed and into a wheelchair. As she was brushing his teeth, she said to him 'I am tired, you have worn me out' (0506).

Maintaining dignity

I noted that in addition to the physical effort involved in washing someone else's body the nurses/ncas also made an effort to do it in a kind and friendly manner.

(2406) Sarah and Nita are washing Peggy in her bed. Sarah stands on one side of the bed and Nita on the other. Nita has on her side a trolley with a water bucket. Nita washes Peggy's body with a cloth and Sarah dries her with a towel. They start by washing her face and then her arms and chest. Peggy is not able to move at all and Sarah and Nita help her to turn when Nita washes her back and Sarah holds her on the side. They always tell her what they are doing and what will come next. They wash her gently, every stroke is done in a gentle way... At one point Peggy says something, her voice is very low and they can not hear what she says. They stop washing her, face towards her and are close to her face and then they hear that she says her legs are sore. Nita puts a pillow to support her feet and Peggy says "that is better". They wash her feet gently and Nita says, "I will just do this gently" and then again "just gently, gently that is it". Another time Peggy says something and this time she tells them that the nightdress they are about to put her in is tight. Nita finds two other nightdresses in her cupboard and asks which one she wants. Peggy chooses one of them. When they have put her into the nightdress Nita says "Yes, this is soft and nice. You have learned which one to use and which one to avoid".

The patient was in a vulnerable condition and totally reliant on the nurses/ncas' effort and assistance. In the interaction of providing physical care the nurses/ncas made sure that the patient was involved in the care as much as possible. The care was always given in a slow and gentle manner.

(2407) Peter is lying on his back in his bed; he wants to be moved higher up in his bed as his feet are touching the bed foot. He has a very sore back and he gets very frightened when he has to be moved, Agnes tells me before we go into his room. Agnes first tells Peter how she is going to do this. She explains to him in a relaxed but focused manner that she is going to move the mattress higher up first and then she will move the sheet he is lying on higher up in the bed. This will bring him a bit higher up. She ask him if this is ok and Peter says "yes". We do this and then she tells him to bend his feet and help us when we move him a bit higher up by putting our hands under his upper body. She asks him again if that is ok for him and he agrees. Agnes's movements are gentle, and when she does this she is not in a hurry but does it in a manner that allows Peter to be able to stop her if he gets too much pain.

I have pointed out how the nurses appeared busy when moving about during patient care. However, when it came to assisting the patient in a vulnerable situation as shown above their effort involved being gentle and slowing down in order to discover how the patient in what way the patient wanted things to be done for him/her.

Another way in which the nurses/ncas maintained the patients' dignity when helping them with personal care was that they would always cover the patient's bed with a screen. I noted that if a nurse needed to speak to a patient and the screen covered his bed she would stand beside the screen and ask 'Are you decent?' before going behind the screen. The ncas or nurses washing the patient would cover the patient's body and say 'yes', then the nurse would go behind the screen and speak to the patient. It was a general rule that it was only the person who was actively involved in helping the patient to wash who was allowed to see part of his/her body naked. Because caring for the body of others involves the exposure of intimate parts, the nurses/ncas paid attention to ensuring the patient's dignity by minimising this exposure as much as possible.

Washing another person's body also means that parts of the body are touched that are usually considered as non-touchable except in intimate relationships. I noted that when doing so the nurses would make excuses for themselves and say things like 'Excuse my hands' or 'Excuse me darling' (0506). It was as if they were saying to the patient that they knew this was not something they should be doing but which they had to, hence the apologies.

The effort involved in helping patients with personal hygiene entailed physical exertion, attending to the patient in a kind and friendly manner, and ensuring the

patient's dignity by minimising the embarrassment of having someone else taking care of one's body.

I also noted that assisting the patients could be demanding on the nurse/nca when they found the patients difficult to handle:

(3110) Amanda is washing a patient in her bed, a lady who is totally bed-bound and has big smelly cancer wounds on her back. Washing this patient and changing the wound dressing can take about 45 minutes. When Amanda has washed her, Neda comes in to change the wound dressings. When doing this, the patient needs to be on her side and Amanda has to stand beside her bed and hold her so she will not fall out of the bed. The wounds smell badly. When Amanda and Neda have made the patient comfortable after the wash and wound-dressing Amanda says to me "I have been taking care of this patient for a few days and I found her very difficult. She was crying and frustrated". Amanda says "I wanted to slap her. I had to ask someone else to do her for the next days. Today the smell was awful. I had to put her down at one point". Amanda tells me "I am going for a coffee and a fag, I need that. I will have coffee in my car".

At the hospice it was accepted that a nurse/nca might 'get enough of a patient'. By organising the care through teamwork, it was possible for nurses/ ncas to have breaks from a particular patient if and when they needed it.

A: You can say to your team members, look I am sorry but I have been doing this person the last two mornings and I could not face doing him today so somebody else would go and do him.

I: Yeah.

A: You recognise that each of us has a breaking point.

I: umhum.

A: And the thing is if you do not want to go and care for someone if you can not give them the quality care you want to give, so if you are not going to give your normal standard you are better to stay back for a day because the next day you could be fine.

I: Yeah

A: And that is how we work it in here. We are encouraged to speak up and say "Sorry but I have had enough" (1202).

It was acknowledged within the hospice that there was a lot of effort involved in the physical care and the nurses/ncas helped each other, they shared the burden in order to cope with these demands. It was a difficult task the nurses/ncas had from early on when they started their shift until 11 a.m..

The atmosphere

I noted that despite the fact that caring for the patient could be demanding on the staff there was usually a certain light atmosphere around the place during the busy period of helping everyone with personal hygiene. There was a buzz around the place and the atmosphere was light and cheerful.

(2905) Abby and Alicia are making Peter's bed in room 5. I walk in and chat to them as they are making the bed. Peter is in the shower. When he comes in he makes a joke and says "Oh these nurses who just attack your bed to make it as soon as you go out of it". We all laugh a bit and then Abby and Alicia continue to chat with each other, Abby is telling Alicia about something she was doing last night. Peter waits while they are making the bed. When they have finished it Peter gets into the bed. Abby and Alicia are in a happy mood and as they chat, they tease each other. They go between the patients in a happy cheery way and offer them help. They do what needs to be done for the patients in a casual and relaxed manner. When they are in room 3 Amanda is there as well. Abby is singing, Alicia and Amanda make negative comments about Abby's singing in a jokey way and they all laugh. (1405) (0406, 0606) The radio is on in the hallway and stays on for the whole morning. Most of the time it is some pop song that is played. At one point I can hear some member of the staff singing a line with the pop song. Audrey and Philip are in front of the elevator waiting for it to arrive. Philip is going home for a home visit. Audrey remarks on the song that is being played in the radio, "Oh this is my favourite song". When I am with Angela helping Petra to have a bath I can hear Norman and Natasha chatting and laughing in the hallway. I say to Angela "Norman is..." before I can finish what I was going to say, Angela says "Yes it is so necessary to laugh". She says, "People say how can you work in a hospice? they think it is all gloomy but it is not". Then she says to Petra "Is it not necessary to laugh?" Petra says "Yes".

When focusing on helping patients with physical care and doing what is needed for the patient, the nurses/ncas often joked with the patients and joked with each other. This caused the atmosphere to be light and cheerful.

(0406) Natasha looks at Philip, who is sitting up in the next bed and Natasha looks at him and says "We need to get this monster into the bath". Philip laughs when she says this. She touches his hair which is all in a mess. She also calls him 'darling' and 'honey'. Natasha and I help Philip in the bath chair and as we are doing this a member of the cleaning staff comes in and says, "Are they treating you ok?" "Oh no" says Philip. "What do you say then?" she asks. "Ooh bug off" says Philip and we all laugh. The atmosphere in the room is cheery and light.

(0110) Alda is walking with a patient in the hallway, another patient is walking in front of them with a stick. "Oh come on, son" she says to the patient in front of them. She passes him and he raises the stick as if he is going to hit her. Alda laughs and so does the patient and Nancy who is standing in the hallway.

It may be suggested that this atmosphere helped the nurses/ncas to cope with the demands of their work, and it may also have helped to lift the patients' spirits to have

nurses/ncas with a positive attitude around them. However perhaps this atmosphere did not facilitate the opportunity for 'being with' in facing death to happen as described in chapter two. This will be discussed further in chapters eight and nine.

The afternoons at M Hospice

In the morning the nurses/ncas went around patients and asked them if they would prefer a wash or a bath. They asked the patients if they were ready now or wanted to wait a bit. The nurses/ncas told me that the patients would not necessarily want to have a bath/wash between 9 and 11 a.m. I noted that it was acceptable if patients wanted to wait until later before being bathed. I saw this happen once when a patient did not have a bath before 11a.m. However, this was unusual. Hence it may be suggested that although the nurses/ncas gave patients the choice of when to have a bath/wash, the routine that was already set at the hospice suggested this should happen between 9 and 11 a.m. and most patients complied with that.

The drug round

Typically by around 11 o'clock every patient had had help with personal hygiene. At this time the nurses would attend to the drug round. Two nurses did the drug round together because they had to double check that the right drug was given to the right patient in the right dose. They would take the drug trolley, where all the drugs were kept, move it from one end of the ward corridor to the other and stop in front of each room. They never took the trolley into the patient's room. One nurse would stand with the trolley and prepare and indicate which medicine was for which patient according to their file. The other nurse would double check if this was right and then take the medicine to the patient and give it to him/her. I noted that the nurse who took the medicine to the patient always attended to the patient in an unhurried, friendly and kind manner and she helped the patient to take the medicine if he/she needed assistance. Sometimes she might need to go and get a drink for the patient to be able to swallow the medicine. Hence it could take some time to go around all the patients during the drug round, usually about one hour for two nurses. After the nurses had

done the drug round they would attend to changing the syringe drivers. Some patients had 24-hour syringe drivers and these would always be refilled late morning or around noon. The nurse would take the patients' syringe drivers into a drug room one after the other and refill them. There were also always two nurses who did this, again to check that the right drug in the right amount was given to the right patient.

The drug round and changing the syringe drivers normally took about an hour and a half, from 11a.m. to 12:30p.m. At this time the ncas wandered about in the corridor chatting to each other. Some of them cleaned the patients' side tables at this time. The patients were offered tea or coffee and usually there was a volunteer who came round the hospice to do that. On some days, if no volunteers came, then the ncas offered tea/coffee.

After the physical care most patients lay in their beds: some of them looked asleep, some of them were unconscious and others were not. A few patients could sit in a chair either in the living room or in their own room. There was a small television in some of the patients' rooms and often it was on. I never saw the patients paying any attention to what was on and they did not seem to watch the television at all.

'Being around'

During the period after the physical care was completed and before lunch was provided for the patients, the nurses/ncas who were not attending to the drug round, acted in a way that made me think they 'were around' at the hospice. They were there in case the patients needed some assistance. The nursing care assistants sometimes wandered about to see if some assistance was needed but I noticed that if they did not have a job to do for the patients they did not approach them.

(0506) After the coffee break all the patients are done and Amy is wandering about in the hallway. She goes into different rooms and chats a bit to the patients and sees if she can do something for them. She helps Pennie who is lying in her bed to drink her tea. Pennie can not move her hands or hold anything as she is too weak to do that, so she can not hold the tea cup. Amy does that and gives her a sip. Amy asks her if she wants the chocolate that is on her table and Pennie says "Yes" and Amy gives her a bit of chocolate in her mouth. When going around like this Amy is focusing on physical tasks that need to be done. At one point she is going into a four- bedded ladies' room when she steps back and says "Oh they

are ok". The patients in the room are all lying in their beds and look comfortable and clean with nothing that needs to be done unlike, Pennie who had her tea cup on the table.

The 'back-shift'²⁰

Lunch is served at around 12 o'clock at the hospice. The nurses/ncas go for their lunch break in two groups, one after the other. The patients who need help with eating their lunch are assisted with that. The nurses/ncas on back-shift arrive at one o'clock. When they arrive the patients have had their lunch and the back-shift go round the patients to do the 'care round'.

(1106) I am following Nicole today who has just arrived on the back-shift, Alicia and she are working together. Nicole tells me that they are going to do the care round. They go round patients in their team and ask if they want refreshments. They help the patients to brush their teeth and make them comfortable in their beds.

Because the back-shift had arrived, the nurses on morning shift were partly released from direct care. They would go for their lunch break when the back-shift arrived, and could attend to more administrative tasks like writing the patients' notes. When the morning shift had had their lunch break the back-shift was freed up from direct patient care and listened to the tape report. The morning shift would be around to attend to the patients if something needed to be done for them for that period of time. The nurse from the morning shift had read into the tape to give the back-shift information about the patients and what needed to be done for them during the back-shift. This helped the back-shift to structure their shift in the same way as the early shift. After the care round and the tape report, usually around three o'clock, the nurses/ncas on the backshift went for a coffee break for twenty minutes and again the nurses/ncas from the morning shift would be around to attend to the patients if needed.

The quietness

The afternoon was usually not as busy as the mornings. The nurses/ncas had less to do in terms of physical care and they often described the situation at this time as 'very

²⁰ The time of the back-shift was from 1-9 PM.

quiet'. They walked around or sometimes sat down in the nursing office for a chat. They were around for the patients if help was required and the focus was on physical care. The nurses/ncas told me that this was the time that patients had their visitors with them. Visiting hours at the hospice were from 2-8p.m. They also told me that this was the time for the patients to rest. So at this time the nurses/ncas did not usually approach the patients unless they needed to do something for them. One of the nurses told me that they did not want to interrupt the patients at this time because they wanted to leave the patients to be able to rest or be with their relatives.

(3007.1) On the back- shift are Nancy, Natalie and Ann. They are walking about in the hallway. A few times some of them say to me "Everything is very quiet". Patients are lying in their beds, some have visitors with them who are sitting by their beds and some of the visitors are reading. The morning shift staff are sitting in the nursing office chatting to each other and I join them. Audrey, Agnes and Angela are all on the early shift and are sitting in the nursing office and chatting. Audrey looks tired and lets the others know that she feels this way. Nora is on the early shift and comes in and out. She is doing some paperwork. Nancy is writing in the patients' journal and Naomi is doing the drug round. They chat about the patients. Audrey is telling Nancy about Patricia who is a photographer and some famous painter has asked her to take a picture of flowers on a mountain next spring. Audrey says "She will not do it, she will not be here anyway". The social worker comes in and Audrey starts to talk to her about a patient who died at St John's Hospital. Audrey says "It was a shame. I am sure he was well looked after there but he was supposed to come here. It is an injustice, we were supposed to look after him." I go to the ground floor and I ask Naomi "How are things?" and she answers "Very quiet".

The back-shift would 'be around' at the hospice in the same way as the nurses/ncas during the time between 11 a.m. and lunch and they would also not attend to the patients unless there was some special task to do for them.

The time is about 4pm and the morning shift is away; I am sitting in the nursing office with Naomi and Angela who are on back-shift. Naomi says to Angela "We have a long night ahead, I will go round". Angela says "I have checked and everyone is ok". "Ok" says Naomi and sits down again. She asks Angela where the care plan is and Angela tells her that Nora the F grade nurse is working on it. Naomi asks "Is there anyone who needs to be turned?" and Angela says, "No I do not think so".

Naomi is the nurse on duty. She is ready to go around to check the patients but when Angela who is the nursing care assistant tells her that she has 'gone around', Naomi sees no point in 'going around' herself because there is nothing to do for the patients. This indicates that even though the nurses/ncas were less busy in relation to the routine activities at the hospice, they did not use that time by showing the patients that

they were available in order to create an opportunity for 'being with' as facing death, if it so happened that the patients was ready for that. If there was apparently nothing that needed to be done for them, the nurses/ncas would not approach them.

Conclusion

I have described what would be a typical day at M Hospice during the observation period, from early morning to late afternoon. It seemed to me, when doing fieldwork and analysing the way the nurses/ncas had constructed their ordinary work, that they had structured it with a certain routine in order to manage the work. They seemed to work to a certain rhythm that was already fixed. The mornings were very busy and the afternoons were very quiet. I have described how during the busy period the nurses/ncas were very focused on the tasks they needed to do and on doing these in a certain way. Neither the busy nor the quiet rhythm of the nurses/ncas' work encouraged them to attempt to take the first step in 'being with' in facing death in the way it is described in chapter two, that is, to show the patients their availability for exploring with the patient his/her imminent death. The nurses/ncas provided structured care in the mornings as described in this chapter, informed by the taped report and managed through teamwork. When not providing structured physical care, such as in the late mornings and late afternoon, the nurses/ncas were around at the hospice ready to respond to situations mostly in relation to physical care. Their availability was limited within this routine. This will be analysed further in chapter six but I will now turn to discuss how the nurses had constructed 'being with', namely as providing comfort.

Chapter Five

Providing comfort

To avoid doing something you only need to consider it done (Baltasar Gracian 1601-1658)

Introduction

In this chapter the analysis of the ordinary work of the nurses/ncas when caring for dying patients will continue as I formulate the way the nurses had constructed 'being with' in a different way from me, namely as comfort²¹ rather than facing death.

Solving the problem

As noted in chapter three and four, much effort and emphasis was put on physical care of the patients and it was evident that the patients benefited greatly from the care they received. The patients were comfortable and without the nurses/ncas' help they would have been in a terrible state.

(1510) Nora is going to help Petra with her wash. Petra is lying in her bed looking very frail and to me it looks as if she could be unconscious but when Nora walks towards her bed she says, "I am feeling bad down below". Nora says, "I will help you to wash". Petra says, "I am too tired to go into the bath. It makes me exhausted". Nora says, "That is fine I will just help you here". Petra's perineum area is covered in cancer wounds and she says, "It is very itchy". Nora washes her perineum area with cold soap-less water and applies some cream. Nora helps Petra to wash and to get dressed into her own clothes. After she has done that Petra sits in her chair wearing blue trousers, a blue blouse and a deep green woollen jumper. She has her glasses on and is going to read the newspaper. She says, "I feel so much better now". She looks very different from the lady she was earlier in the morning, lying in bed and looking incredibly frail and in discomfort.

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I am indebted to Raffel's (1984) paper that inspired me to formulate the way the nurses/ncas constructed 'being with' as comfort. In his paper he shows how close reading of Dr. Benjamin Spock's famous book "Baby and Child Care" raises the possibility of Dr Spock treating parents by comforting them.

The structured care in the mornings was aimed at helping the patients to maintain their personal hygiene, and despite their lack of control over their own body functions and the weakness of their bodies their dignity was maintained. As noted in chapter four, when it came to 11 o'clock in the morning usually all the patients had been helped with personal hygiene and the atmosphere became quiet. I noticed when walking along the corridor that the patients looked comfortable. Some of them were wearing their own clothes and sitting in chairs either in their room or in the conservatory/sitting room. Others who were unconscious and/or unable to get out of bed were lying in their beds and looking clean and comfortable.

(1605)I pass Paula's room and she is in a single room at the end of the hallway. She is dying. Her breathing is short and she does not react to Nellie and Alison who are in her room and have just finished washing her. Her room looks clean and fresh and also she looks comfortable as she lies in her bed. Alison is cleaning Paula's mouth and Nellie is putting up a small air conditioner beside her bed.

It is hardly possible to imagine the patients without the care they received, as they were dependent on help in order to manage routine personal care and to have their basic needs for personal hygiene met. The nurses/ncas at the hospice were always ready to respond to the patients either with the structured care as described in chapter three or by 'being around'. Patients were helped to become clean and comfortable. I observed that this focused the care around solving the problem of discomfort.

As noted in chapter four the illness could cause the patients to be in discomfort related either to physical weakness and loss of bodily function or to the symptoms of their disease. I saw that when going about the care in the way they did, the nurses /ncas most often succeeded in meeting their expectations of ensuring comfort and pleasing the patients. For example I observed Andrea helping to turn a patient in his bed. The patient was so thin that his bones were sticking out of his body. To maintain comfort the patient had to lie in a carefully made position. I observed how Andrea put 6 pillows in a certain way around the patient. Some pillows she rolled up so they would be a better support for the patient e.g. behind his back. Others she put under his arms or between his legs. This took a while to do and in the end the patient whose face had looked strained before she did this was smiling and obviously happy with how she had arranged the pillows around him. The nurses/ncas could always solve the

problem that was causing the patient discomfort, and ensuring his/her comfort was most often the outcome of the interaction.

I noticed that the focus of the nurses'/ncas' interaction with their patients, was the ability to respond to their discomfort and solve the problem. For example I once observed a patient complaining about pain to the nurse and the nurse reassured the patient that she did not need to be in pain because she was at the hospice.

(1906) Pat says to Noreen, "I am so tired today but I did have a smashing day yesterday but now it is like square one again". She is tearful when she says this. Noreen sits down on her bed, holds her hand and says "Are you fed up" and Pat says, "Yes, I felt smashing yesterday but now it is back to square one". Noreen looks at Pat face to face, tears start to roll down Pat's cheek. She says "The pain is from this place to this" and points to where she feels the pain. "If it could only stay at the same place... if I did not have this pain I would be fine". Noreen says, "Is something else bothering you?" Pat says "No". Noreen says, "You have to let them know immediately if you have pain because it is much better to get rid of the pain then". Pat says "But you are so busy". Noreen says "No, this is what we are here for and this is the reason why you are here, we are trying to control the pain. You have to promise me that you will let us know as soon as you start to feel the pain." Pat says, "Yes I promise". Noreen goes away to get the painkiller for Pat.

As I will further develop later it is noteworthy that Noreen does not pay attention to the fact that the patient is expressing her feelings related to having such a pain. She only focuses on the solution, that is, to reduce the pain with medication rather than discuss with Pat the meaning of the pain. (Increased pain may indicate the progress of the disease and may be a reminder of the fact that the patient has an incurable disease that will lead to his/her death).

I noted that throughout their shift the nurses/ncas were focusing on problems that revolved around physical matters arising from a patient's illness. Most often they responded to these without hesitation as Noreen and Andrea did. They knew what to do in order to solve the problem. The nurses/ncas were busy trying to manage the discomfort of the illness and make things better for the patient. The nurses/ncas could normally provide some solution to the physical problems that the illness caused patients. Usually the patients were not in pain, and if they were, they were reassured that this did not have to be the case. For example, Noreen explains to Petra that she needs to let them know as soon as she starts to feel pain so they can sort it out.

The patients are 'childlike'

I noted that the nurses/ncas were mostly sure what physical care was needed in order to ensure the patients' physical comfort. They did not hesitate or mull over what needed to be done, they knew and most often responded quickly even though they sometimes showed a controlled calmness when caring for vulnerable patients, as noted in the previous chapter. This became evident in their confidence that they knew what to do for the patient better than they did. The patients had confidence in the nurses' knowledge of what would be best to do. For example, one time a patient asked a nurse for a painkiller and the nurse asked the patient if she wanted a certain type of painkiller. The patient answered, 'Whatever you give me, nurse'. I also noted that the nurses/ncas were often sure of what the patient needed even though the patient could not communicate that, and their response was appropriate and successful in ensuring comfort.

(1405) I follow Amanda into a four-bedded ladies' room. One of them is lying in her bed and looks very frail. She starts to move around in her bed and seems uneasy. Amanda asks her what she wants and she leans forward so her ear is close to the lady's mouth. The patient says something but Amanda says "I can not hear you, you know this is my deaf ear". When she says this the lady gives a big smile and Amanda kisses her on the cheek and asks her, "Do you need the toilet?" The patient did not respond but Amanda goes and gets a toilet chair. She urinates a lot so she obviously needed the toilet. We help her into bed again and Amanda gives her water to drink. Amanda takes a comb out of her pocket and combs the lady's hair. After this the patient is calm but says she is sore. Amanda tells her, "I will ask them to come and give you something". The patient gives Amanda her hand and says "thank you". Amanda kisses her hand and then goes away to ask the nurse to give the patient something for the pain.

The nurses/ncas would keep an eye on the patients as they were providing nursing care. They were constantly focusing on whether the patient needed some help due to lack of physical strength or whether the discomfort terminal illness causes was being managed. Sometimes the patient was unable to tell them but the nurses/ncas would be able to anticipate what the problem was as the extract above shows. Furthermore they would not necessarily wait until the patient complained about something or asked for help. For example, when I was following a nurse she unexpectedly attended to a patient in one of the beds and asked her if she was in pain. To me it did not look as if the patient was in pain. The patient said 'yes' and the nurse went to get a painkiller, which she gave to the patient.

The nurses/ncas would often suggest what the patient should do and the patient would accept that. Sometimes this appeared in a humorous way as shown in the extract below.

(1605) I walk into room 2. Alda is there making Patricia's bed. Patricia is sitting in a chair. I help Alda to make the bed. While we are doing that Natasha comes into the room and she asks Patricia if she is going to sit in the chair for a while. Alda says "She is getting into bed". Natasha says, "Oh no, you are not going to bed"; then she puts up the head side of the bed in an upright position and says "Oh at least you are sitting up. Alda is a softy". Patricia says, "Yes and you are a wee bully".

This seemed to me like a relationship between a child and a parent rather than between two adults. The nurse/nca was like a parent and the patient like a child, as is very evident in the extract below.

(2205) The physiotherapist and Nancy are standing beside Pedro's bed. The physiotherapist says, "They are waiting for you, you naughty boy". Pedro does not say anything and does not make any attempt to move but obviously the physiotherapist wants him to go somewhere and has brought a wheelchair. Later I learn that they want Pedro to go to the day care unit and I see someone driving him in there.

This perception of the patient as a child became apparent in the nurses/ncas' language and they described the patients as 'boy' and 'girl' and talked to them the way that children are talked to.

(2205) Audrey and I go into Paula's room to help her to wash. Paula has very itchy red skin. Audrey tells me that because of that she will use cold water and no soap to wash Paula. For most of the time Paula sits in the chair when Audrey washes her. Her skin is very red and Audrey touches it gently and says, "Oh, it is so sore". When she helps her to wash her bottom Paula needs to stand up. When this has finished Paula sits down again and Audrey says to her "That is it girl, are you okay, darling?" When choosing clothes for Paula Audrey says "Oh your light blue dress is so nice, are you gonna be a lovely wee girl today?" Paula says nothing but we put her in the blue dress and Audrey says "Oh, it is so nice". Audrey combs her hair very gently saying, "Oh it is so sore".

I noted that the nurse/nca sometimes treated the patient like a small boy or girl. The nurses/ncas often called the patients 'darling' or 'honey' when doing something for them. For example they would say, 'That's it, darling' or 'Is this ok, darling?' when they had finished helping a patient with something. I noted they sometimes tried to

downplay what was happening by using the word 'wee'. Nadia did this when she gave a patient an injection. 'I am giving you a wee jab to make you comfortable' and then after she had given the injection she said 'That is it, girl'. I also noticed that it seemed that the nurses/ncas felt sorry for the patients. For example, when they talked about a patient to me or with each other they often remarked 'He is so lovely' or 'He is such a wee soul'.

Caring for patients makes the nurses/ncas feel good

It also became apparent when talking to the nurses/ncas that being able to provide comfort made the nurses/ncas feel good as well; as Audrey told me:

(0202)..and it gives you a feeling of niceness really you know. They are asking you to do things for them and it is great to be able to do that, you know. They can't get out of bed, they can't feed themselves. It gives great satisfaction seeing someone eating when you are giving it to them, you know. I like doing that, I like feeding and I like reading to them their cards, things like that.

The nurses/ncas attended to the patients in a gentle manner and helped them to do things that they could not do for themselves. They found it a worthwhile job to do because they knew that the patient needed the assistance they were giving and would be in a much worse situation if they could not get the help from the nurses/ncas. Amanda spoke to me one day:

(1012)If I am feeling down myself and you maybe have had a couple of shifts that have been really crappy shifts and you say to yourself, Why am I doing this job? and then you come in the next day and you are maybe bed bathing a patient or something and they turn and say, You know, Amanda, what would I do without you? And it just gives you a lift and you think that is what I am here for. They acknowledge the care they are getting and their appreciation of the care emmm it gives you a boost and makes you think that your job is worthwhile.

The patients needed the help that the nurses/ncas provided and they were grateful for the care; their relatives also showed that they were grateful for the care their loved ones received at the hospice. In the nursing office on both of the wards there was a pin-board where cards from relatives were pinned up. These cards were usually from relatives of patients who had died at the hospice. The relatives sent these cards to thank the nurses/ncas for the care the patients had received at the hospice. They often

said in the cards how important the nurses/ncas' kindness was for the patient. The patients were grateful for being cared for in a way that ensured their dignity and comfort. And this was obviously important for the nurses/ncas as Amanda told me:

(1002) You get the feedback from the patients or their families. I mean when the people die and their family sends you a card and they say, in fact we got one today. From a niece of a patient who died just the other day here and she actually stays down in England so she had said in her card that thanked us for the care we had given to her aunt. Every time she spoke to her on the phone her aunt said it was like living in a five star hotel and she felt like a film star. Reading that it makes you get goosebumps and you think you know people do appreciate you.

I noted how the nurses/ncas were committed to making patients feel better as both Amanda and Alicia told me. It was the indicator of having done a good job as Alicia commented.

(0312) To me if they are settled and they are cared for it gives me a lot of satisfaction..... if I can see them nice and settled and their family is happy because they are settled..... I think your job satisfaction is if you can see they are comfortable.....

'We will talk him through it'

I noted in relation to physical comfort, the nurses/ncas would push the patients through a bit of discomfort, with an attitude of kindness and gentleness. For example, Nellie told me that one of the patients she was looking after found it difficult to have a bath. The patient was bed-bound and therefore when having a bath the nurse/ncas would put him into a hoist sling when transferring him from his bed into the bath. Nellie told me that the patient got frightened in the hoist sling because he had been trapped somewhere earlier in his life. She said to me in a kind and confident voice, 'We talk him into it, we talk him through it'. (1006).

To ensure comfort as a result of hygiene, the nurses/ncas would kindly and gently push the patient through a bit of discomfort in order to establish longer-term comfort.

(1610) Noreen goes into Patrick's room. His bed is behind the screen and Noreen says, "What is happening here behind the screen?" There is no answer but Patrick groans and Noreen goes behind the screen. Patrick is totally bed-bound and he has wet his bed. Alda and Amanda are helping him to become clean again by washing him and changing his bed. Patrick groans a lot as they are

doing this. Noreen goes over to the head of the bed and holds his hand. She says "It is ok, it is ok". Amanda is at the bed head on the other side and holds Patrick when he needs to turn on his side and she also holds his hand. Alda washes him, puts cream on the red skin. There is a blue plastic cover over the mattress and she cleans that with a wet cloth, dries it and then puts a clean sheet on the bed. All her movements are fast but gentle as if she is trying to do this as quickly as she can. Amanda and Noreen hold each of Patrick's hands and encourage him telling him that this will soon be finished.

When assisting the patient with personal care related to his hygiene the nurses/ncas try to make the patient feel good about what has to be done for him, to minimise the embarrassment of what has happened as a result of loss of body function. There was another occasion when Audrey was helping a patient who had wet his bed.

(2205) I go with Audrey into Peter's room. When we come into the room Peter is trying to get out of his bed and Audrey says to him "Do you need the toilet?" and gives him the flask. Audrey notices that Peter has wet his bed. Peter says "I am sorry" and his face looks sad. Audrey says with a happy voice "That is ok, don't worry". Audrey goes out of the room to get things to wash Peter and a clean sheet. She is away only for a couple of minutes. When Audrey is away Peter says to me "It is the cancer, you know, it does not go away". I am just about to say something when Audrey comes back into the room. She approaches Peter's bed in a happy cheery way and starts to wash him. She helps him to sit in a chair while she changes the bed-sheets. While Audrey is making Peter's bed he says, "I did not sleep well". Audrey says with a kind and cheery voice "We will pop you on the bed after this". Audrey helps Peter back into his bed. She helps him to lie on his side and puts three pillows under his head and one behind his back. He looks comfortable and clean and closes his eyes as if he is going to sleep. When we go out of the room Audrey says to me, "He is so lovely".

Audrey knows that it is embarrassing for Peter to have wet his bed and she wants to minimise the embarrassment by showing him that she is happy to help and he does not have to be sorry. She will sort things out. He is in a vulnerable situation and is not able to control his own bodily functions but she tries to avoid making him feel bad. Audrey tries to make him feel better about what has happened by saying it is okay and in a cheerful, happy mood helps him to become physically comfortable again. Audrey washes Peter, puts clean sheets on the bed for him and once more makes him comfortable in bed. He is relaxed and ready to sleep after the care.

Positive outlook

As noted in the previous chapter the atmosphere at the hospice was light and cheerful. This often became evident in the joking interaction between the nurses/ncas and the patient. For example, when Natasha was in a four- bedded room making a patient's bed, Peter was in the next bed sitting up and his hair was dishevelled. Natasha went over to his bed, messed up his hair further and said, 'Look at you! We need to get this monster into the bath'. Peter laughed. The cleaner came in and said to Peter 'Are they treating you okay?' 'Oh, no' said Peter. 'What do you do then?' she asked. Peter answered, 'I just say, ohh bug off' and laughed (04.06).

This made the atmosphere at the hospice friendly and light. I noted that when the nurses/ncas were around the patients they were usually happy and cheerful. This continued when they were talking to the patients. When having a conversation with the patients they maintained an upbeat mood and had a positive outlook on things. For example, when discussing the approach they used in caring for the patients at the hospice the charge nurse told me 'Not every patient wants to have someone with the 'church image' asking "How do you feel?" Or saying "It must be awful". They want to feel normal otherwise they think it must seem awful to me'(0210). The nurses/ncas tried to maintain a positive and normal atmosphere by relating to the patients in a humorous way but also in a relaxed and casual way as shown by this extract.

(1706) I follow Nora into Patrick's room. He is sitting in a chair beside his bed. He tells Nora that he has a terribly dry mouth. Nora asks "Does the spray not help?". Patrick says, "Yes for a while but I go through it very quickly". "That is ok" says Nora, " we can find a way round that". She takes a spray that is on Patrick's night table and gives it to him. He uses it and then she says, "I will order a couple for you". Nora talks about football with Patrick. His son plays football and is in the school team. On the wall beside Patrick's bed is a picture of his son's football team. There is also a picture of three children and Nora asks, "Are these your grandchildren?" Patrick says "Yes". Nora looks at the picture and looks adoringly at the 3 little children in it. Nora asks Patrick if the socks he wears make a difference and Patrick says "No". Nora looks at his legs as Patrick tells her how swollen they are. There is a newspaper lying beside his feet and there is a big headline, "60% discount on flights to Ireland". Nora is Irish and she is obviously paying attention to the article. As she does that she says, "Sorry, I am hearing what you are saying but I am just looking at this". Then she stops looking at the paper, looks at his feet again and says "Yes, they are swollen, do you not want to wear your socks?" Patrick says "No, I am going for a walk". " Ok, I will not bother you about that then" , says Nora.

On other occasions I noted how the nurses/ncas were directly trying to focus on something positive and through that trying to avoid giving the patient the feeling that the situation he/she was in was awful.

(2506) Naomi is helping Patricia to have a bath in the bathroom. Naomi washes Patricia's hair while she is sitting in the bath. At one point Patricia starts to cry and Naomi stops washing her hair. She puts her arms around her and says, 'We all need to cry, and laugh'. Patricia stops crying and Naomi carries on helping her with the bath. Then she helps her to get out of the bath and to dry herself. When she is helping her to get dressed Naomi asks Patricia about her family and whether her daughter has a boyfriend. Patricia says "Yes" and Naomi asks, "Is he a nice chap?" Patricia says "Yes" and then she starts to cry again. She says, "The doctor made me cry". Naomi says, "It is good, we need to cry". Then she says, "Have they been together for long?" Patricia says "Yes" and Naomi says, "That is good". Patricia does not say anything to this. Naomi says, "We will give you tea and a cigarette, then you will feel better". She says this in a soft and comforting voice. When Naomi has helped Patricia to get dressed after the bath her face looks more relaxed and she is not close to tears or looking sad as she was when having the bath. She jokes about the Ribena she spilled on her bed. When Naomi is pushing Patricia out of the bathroom in the wheelchair I can hear that she says something about volunteers and coffee that I don't understand. Later after Naomi has helped Patricia with the bath, she meets Nadia in the hallway and remarks about Patricia, "She is all over the place". Nadia says, "Yes she was also very emotional yesterday". Naomi says that there are no volunteers to serve the coffee today and she says that she is going to serve the coffee.

When Patricia starts to cry, Naomi attends to her crying by saying that everyone needs to cry but she also reminds Patricia that laughter is necessary as well. She changes the subject to something that she thinks will be positive for them to discuss. Naomi turns the conversation to Patricia's family and the fact the Patricia's daughter has a nice boyfriend. When Patricia starts to cry again Naomi tells her that this is okay but she continues to discuss Patricia's daughter and her boyfriend. Perhaps Naomi is attempting to say or do something that provides emotional comfort in pointing out that Patricia does not have to worry about her daughter because she has a nice boyfriend. She also points out something she is going to do for Patricia which she thinks will comfort her. She tells her, 'We will give you a cup of tea and a cigarette; then you will feel better'.

The nurses/ncas wanted to try to make the patients feel better about the situation they were in. In doing so they were often optimistic and tried to reassure the patient if they noticed that the patient was worried, as Andrea did in this extract:

(0506) Andrea is in room 3 which is a four-bedded men's room. Agnes is there and she and Andrea joke with Peter who is lying in his bed. They are all laughing and chatting. Paul is sitting on his bed in his own clothes. He is going for a home

visit. He does not respond to the jokes and he looks anxious. Andrea goes over to his bed and says to him, "You will be fine".

It became evident that the nurses/ncas' approach to caring for the patient made the patient feel comfortable about having to be in a hospice. Andrea told me that the hospice was not all about death and people actually got better at the hospice. She gave me an example of a patient who had been very down and had not wanted to be at the hospice but was now chatting and happy. She also gave me an example of another patient who came into the hospice whereas the home care nurse had said to the nurse/nca that at the beginning the patient was resistant to being in a hospice. When the home care nurse came to visit the patient at the hospice, a few days later, the patient said that she thought that the people there were lovely and that she wanted to stay at the hospice. Andrea told me, 'That made me feel good'.

When in the hospice I sensed for myself that the laughter, the jokes and the way the nurses/ncas went about providing nursing care in a relaxed and happy manner helped to create a positive atmosphere. It became evident that the nurses/ncas were trying to make it more bearable for the patients and themselves to be in the hospice. The patients gained physical comfort through care provided in a kind and gentle manner and in an atmosphere that was positive and friendly. This was the aim of the care and what they wanted to achieve. The charge nurse, told me:

(2101) The biggest compliment is that people who really do not want to be here but can accept that... you know.. "I am enjoying being here. It is not the first place or ideal place but I am getting enough comfort from here to acknowledge that I am better here than at home".

The nurses/ncas put emphasis on giving the impression of the hospice as a good place to be in, and when it was evident they had succeeded, they felt good about themselves and the work they did.

Death- the ultimate comfort

Because of the nurses/ncas' effort to keep the atmosphere in the hospice light and cheerful the atmosphere was not associated with death which is normally viewed with sadness. When coming into the hospice I could not tell that death was a day-to-day

event in this place. However, this was the case: for example, 277 patients died during the year 2002. It only became apparent to me that death happened frequently in the hospice when I spoke to the nurses/ncas. For example, when I arrived at the hospice after a one-week holiday and asked Audrey what had been happening she told me that 5 patients had died during the week I was away (3010). When I once arrived on a Monday morning, after a weekend break, Andrea told me a patient had just died that morning and a nursing care assistant told me that over the weekend four patients had died so this was the fifth death in three days (0411).

Death is simple

I have described in this thesis how the nursing care was provided in a structured and routine way at the hospice. The approach to care was focused on what needed to be done for the patient physically and this was organized into a routine. I noted that the nurses/ncas continued this approach when the patient had died.

(3009) After the tape report Nadia goes into Peter's room. Peter has just recently died. Natalie is in the room and she says to Nadia, "I took the needle from the morphine pump, I think there is nothing else we need to do". Nadia says, "No, I don't think so". Natalie says, "I am going to tell the relatives that they can come back in now".

The fact that someone had died did not affect the day-to-day structure of the care work. The usual routine was carried out in an undisturbed way.

(3110) Peter has just died. Naomi says, "Before I go in there I am going to have a fag while his parents are inside with him. He is clean and everything, we will just go in there [to take care of the body] when they are gone. I will have a fag first". (3110) Naomi and Alicia come out from Peter's room after having taken care of his body. Naomi says to Nancy, "I am going for my break and then I will help you with the pills".

Alda told me how she tries to avoid paying too much attention to the fact that the patient is dead because she has to carry on with the work of making the body of the dead patient clean, e.g. by brushing teeth or combing hair. She also told me how she still keeps her kind and friendly attitude towards the patients after they have died and said with a kind voice 'I say things to them like, "Close your eyes, dear" when trying to close their eyelids' (0110). This also became evident in Audrey's account:

(2207.1) *Audrey has been handing over four bodies to the undertakers over a short period of time. She tells me how different the undertakers are. "When they came to collect Paul [who has been at the hospice unusually long, 10 months] they lifted him over by holding his arms up. She shows me how they did this and she has an expression of horror and says "poor Paul ". The chaplain comes into the coffee room and Audrey tells him this as well. Then she says, "But the other undertakers are so gentle, they do it so gently".*

The nurses/ncas also continued their gentle way of speaking about the patient. For example, they would say to me after a patient had died, 'He was such a lovely guy'.

After the patient's death his body was cared for with the same attitude as when he/she was alive, in order to maintain dignity. It was done with gentleness and kindness as well as focusing on hygiene.

I also noted that the nurses/ncas kept up their cheerful, positive mood, as described in chapter three, when patients died. For example, once I was following a nurse who had just started her back-shift. She went into a patient's room. When we were in the room we both noticed that the patient was dead. The nurse looked at me and nodded. Another nurse came into the room with the patient's relatives. We were only in the room for a couple of minutes. When we were out of the room, one of the nurses said to me, 'We will give [the relatives] some space'. I followed them into the nursing office to listen to the tape report. When sitting in the nursing office they laughed and joked with each other and did not mention what they had just experienced, i.e. that one of their patients had just died.

This was also the case when a patient who had been at the hospice for a period of time got more seriously ill and was dying. For instance, on one occasion when I came to the hospice one of the patients, who had been at the hospice for a couple of months and always dressed in her own clothes and sat in a chair, was now lying asleep in her bed. The patient did not respond to me when I tried to greet her and had clearly deteriorated since I was last at the hospice. When I mentioned this to the nurse she said in a bright way, 'Oh yes, this morning we did not wash her until around eleven; she was so cuddly in her bed, I did not want to disturb her'. Not much attention was paid to the fact that someone had just died or that a patient was getting closer to death as long as the patient was comfortable.

The hospice was a place for dying patients and in fact if the patient was not dying he/she might soon be referred somewhere else. For example, when discussing a patient who was waiting for admission to a nursing home, the nurse said to the doctor, 'He is starting to realise that he is too well for here'. (1906.2). Death was an ordinary day-to-day event for the nurses/ncas at the hospice. The patients at the hospice were expected to die, that was why they were there. I could hear remarks such as 'She is dying now' (1706) said in a casual way when the nurse and the doctor had their morning meetings, or in a more surprised way 'Oh is she still here?' (1706) or 'Is she not dead yet?' (1405). It did not surprise the nurses/ncas if a patient died, in fact it caused surprise if the patient didn't die that day. I experienced this at a multidisciplinary meeting when a patient who had been at the hospice for five months was discussed. Everyone looked at each other in a puzzled way and someone made the remark that this person should have been dead long ago (2904). Death was an expected part of the day-to-day ordinary life at the hospice and it was more surprising if it didn't happen. The nurses/ncas saw death as a good thing for the patients who had died. As Alicia told me, 'It is actually more the family you feel for than for the patients. They are getting the relief in the end, aren't they?' (0312). Death was seen as simple at the hospice and furthermore as a positive thing.

I noted that death was seen as moving things on for the patients. One of the nurses on one occasion said to the other nurse after a patient had died, 'I am glad for him that things have moved on, he was such a wee soul' (0309). Death was seen as a solution for the patient, an event that would enable the patient to achieve total comfort, as Audrey's account shows:

(0202)I see death.....as emm not as a pleasure but a relief for a lot of them, the ones that are... well are not suffering physically because obviously you know hopefully their pain is all under control but mentally there is a lot of underlying mental suffering. But they are so brave, they don't come out with that a lot but you can tell, you know the ones that are in mental anguish -not all of them but most of them. You think, [when they die] oh I am so glad, you know. To an outsider who does not understand the situation, Erna, they would think you are glad that a person died, you know. And you say, Yeah they were so miserable, you know, and needed to die. Like Patricia, she is like a cat lying in her gutter; you know she is just getting worse and worse and she is just lying there and there is no bitterness and she really needs to go now. It is awful for her son and husband. They are coming day after day seeing her like that and she does not want to be here either and that saddens me.

I also noted that in terms of the overall nursing care for the patients, it could be good if patients died. Caring physically for dying patients can be demanding, as shown in chapter three, and could be more demanding as the patient gets closer to death due to an increasing lack of physical strength. The death of a patient could mean that the organisation of the overall care for other patients at the hospice became more manageable because the burden of care on the nurses/ncas became less.

(3009) Nita comes in to the nursing office and says "Anything about the staff today?" [there is a staff shortage on the late shift]. Nadia says "Oh it will be ok, I will muddle through". Nita says, "You will not". Nadia says, "Oh we will not have Peter" [he has just died]. Nita says, "Oh that is right".

Furthermore, a death could mean that patients who were waiting to come into the hospice could do so. For example, at a planning meeting the charge nurse said, "Four patients have died so we have free beds". (0411). On another occasion when the charge nurse was telling me about two new admissions to the hospice, she made the comment that it would probably be alright because two patients had died over the weekend. Death was some kind of solution in two ways: for the patient who had died and had gained total comfort through death, and for another patient who, because someone else had died, was being cared for and could gain comfort through the nursing care.

Providing a specialised palliative care service?

The nurses/ncas saw this way of caring for the patients and the outcome of the care they were providing as specialist palliative care. They emphasised that this was the kind of care they were providing at the hospice.

As already noted the hospice had been a nursing home in its early days, but the history of the hospice as a nursing home and a palliative care service was a bit blurred. When I asked the charge nurse when the changes had occurred she did not know exactly when this had happened. There did not seem to be a clear turning point in its history. However I noted that it was important for the nurses/ncas to know that what they were providing was specialist palliative care. For them, a specialist palliative care service included symptom control. That appeared to be the main criterion for the patients' being at the hospice. They had to have a terminal illness and

be close to death and/or have some symptom of the disease that needed to be managed. These conditions differentiated the place from a nursing home.

(0406) In the nursing office Natasha, Noah and the physiotherapists are having a discussion. Natasha is complaining that the plan for someone to be discharged has not been carried out properly. She says, "He was ready to go to the nursing home but we missed that. This is meant to be specialist palliative care not a nursing home. If people do not need specialist palliative care, they should go to a nursing home. I mean, I have nothing against caring for old people but this is palliative care here". The physiotherapist says, "But fatigue is a syndrome that we are dealing with. If the patient has so much fatigue it is appropriate to deal with that here".

If a patient was not very close to death it had to be clear to the nurses/ncas that the patient needed certain symptom management since that was why the patients were at the hospice instead of being discharged to somewhere else. As discussed in the literature review, the palliative care philosophy evolved around managing the symptoms that the disease causes patients. If the patient had a symptom like fatigue he/she could be at the hospice but if not, he/she should be somewhere else. The care that was provided at the hospice was seen as the appropriate care for the patient if he/she might not get it except in a specialist palliative care unit.

(1006) Nellie is the nursing team leader on the ground floor. She has been at a meeting with the medical director and is now sitting in the nursing office with the nurses and nursing care assistants who are on duty. At the meeting she tells them that the doctor was raising concerns over how the staff were feeling about looking after Pat. Maybe they are thinking that she does not need specialist palliative care but should be in a nursing home? "His opinion", says Cathy, "is I agree that she needs this environment here in order to get her pain relief. When she asks for it she gets it even though she does not look in pain. In another environment she might get a different response and that would put a lot of stress on her. She would not cope with that. She is balanced in this environment and that is why she needs it." Everyone agrees and says they feel okay about nursing her.

I noted that for the ncas, being able to attend to the patients in an unhurried way, maintain their dignity as described previously and give them all the time they needed was seen as part of specialist palliative care. It was evident that the unhurried and gentle way they cared for the patients took more time. One nursing care assistant told me that the nurse manager that had been at the hospice before had admitted many more patients to the ward than the current managers. She told me that before they had to rush between patients to be able to help every one with a bath or a wash, whereas now they have much more time for each patient. Then she told me, 'We have to, this

is a specialist palliative care unit'. Another nursing care assistant told me that on the ward they would always take the time needed to attend to a patient 'Because it is a specialist palliative care ward, not a busy medical ward' (0212). Another said that the nursing care at the hospice was much better than at the hospital because they would take time to feed the patients and pay attention if they needed help with mobility. A patient's husband had told her that in the hospital the food was just put in front of his wife even though she could not eat it without help. They would just come back a little later and take the tray away even though she had not touched the food. The nursing care assistants said, 'We would never allow that to happen here, we would say "I will give you a wee hand with that"'. Being able to give the time that the patient needed when helping him/her with physical care was important and seen as part of specialist palliative care. Moreover, every patient at the hospice was considered to need specialist palliative care including symptom control. If this was not the case they would be referred somewhere else because, as a nurse said about a patient who was bed-bound and had pressure sores, 'We are planning where she can go to in the future, as we are not doing anything actively for her' (3009). To be doing something 'active' in the sense that has been described in this chapter was important for the nurses/ncas.

Conclusion

In this chapter I have shown how the nurses'/ncas' expectation of their own work at the hospice was to provide comfort. This was in accordance with the hospice philosophy which had as its aims to provide comfort through care and minimise the discomfort the disease might cause the patient, to reduce the patient's loneliness and isolation through human contact, and to maintain the patient's dignity despite his/her physical disability through kindness. However through this hospice's way of constructing the care there was a clear emphasis on prioritising the physical aspect of care.

The charge nurse confirmed that physical care was the main aspect of the nursing care at the hospice when she told me that most of the nurses/ncas' work at the hospice, or 85% of the care, was around solving practical issues, most of which related to physical care. The main reason for this was the nurses/ncas' obligation to respond to

the effects the illness had on the patients' physical state and this took up most of their time and attention. 'For example, all of a sudden Paul needs some pain medicine because he is in extreme pain'. (2101). The nurses/ncas managed this by structured care and by 'being around' at the hospice ready to respond if a patient needed help related to his/her physical disability or discomfort, as described in chapter three, and as a result of this the patients were kept physically comfortable, as described in this chapter. However one aspect of Saunders' philosophy was not evident in the care: encouraging the patients to face death through 'being with' them, as I described in chapter two. By constructing 'being with' as providing comfort the nurses/ncas could avoid 'being with' as facing death without recognising that something was missing from the care. However if they were to consider themselves as providing a specialist palliative care service they would have to include this aspect into their care. In the next chapter I will show how the nurses/ncas in the field where I did my study did not pay attention to signals that showed patients' emotional distress. Within the analysis I hold on to my own understanding of 'being with' based on Saunders' notion of facing death.

CHAPTER SIX

Missed opportunities

Introduction

In previous chapters I have described how the patients' comfort was ensured at the hospice through the nursing care they received. Despite the fact that the hospice is a place where patients die, it seemed a good place to stay in. The nurses provided care in a kind, gentle and confident manner and this was well received by the patients. This made patients comfortable and they were grateful for the care. However, as noted in the beginning of this thesis, I was aiming to investigate certain aspect of Saunders' philosophy. In the previous chapter I showed how the nurses/ncas in M Hospice understood 'being with' as providing comfort rather than facing death. I will in this chapter focus on the consequences this had on the patients' care, through the methodological argument of interpreting data while holding on to my own understanding of 'being with' in facing death as formulated in chapter two.

Limited availability

The attention is focused on providing physical comfort

I noted that the interaction between the patients and the nurses/ncas was in regard to providing physical comfort. They would not usually spend any longer with the patient than the physical task required. Furthermore, with this being the focus of attention, the nurses/ncas would relate to the patient in a certain way. The main aim of the engagement was to provide physical comfort and the nurses/ncas were preoccupied with that, e.g. when Audrey engaged with Peter when he had wet his bed (see extract in chapter four p. 111). Audrey responded to the situation in the manner in which the nurses/ncas usually operated at the hospice when attending to the patient's physical

discomfort. She became busy doing something for the patient, which would actively solve the problem the illness was causing the patient. That was evidenced in this case when the patient had wet his bed. She was also cheerful and did what was needed in a gentle manner. Peter's face was sad when this happened and he apologised for what had happened by saying, 'I am sorry, I am sorry'. But Audrey said, 'It is Okay, it is Okay' in a cheerful voice. She made him feel better with her happy, light manner and gentle, confident approach which made him clean again. When Audrey went out of the room to get a clean sheet etc. I stayed with Peter and remained silent. Peter said to me, 'It is the cancer you know, it is moving around and does not go away'. Peter was starting to tell me how he saw the situation. He gave me a cue, which I noticed and wanted to pick up. Maybe he wanted to talk about how he was feeling? Also for me another cue was Peter's sad face which indicated that what had happened made him feel bad. However before I had an opportunity to respond, Audrey came back into the room and cheerfully started to do what was necessary for Peter to be clean and comfortable again. However, this did not give Peter the opportunity to continue to telling how he felt. When Audrey came back, Peter stopped talking about his situation. Because I was in the hospice in the role of a researcher I did not think it appropriate to say to Audrey when she came in, 'Peter was telling me about his cancer' as I would have done as a clinical nurse in this situation. I would have tried to 'slow Audrey down a bit' by bringing Peter's feelings to her attention and encouraging her to allow for the opportunity to address these.

What Audrey did for Peter may have made him feel better about what had happened because Audrey is kind and helpful. She took care of the situation and sorted out the problem for Peter. However, he kept looking sad and he was not given an opportunity to talk about how he felt about what was happening to him, i.e. that he did not have control over his own body functions because he had a terminal illness. Audrey's engagement with Peter involved taking care of what had happened and she did that in a respectful manner as described in chapter two. Her effort went into dealing with the practical aspects of the situation in a kind, gentle way that took absorbed her attention. All her effort was channelled into helping Peter to become comfortable. I was not operating in this way and Peter's care was not my responsibility. When Audrey went out, I just stood silently beside Peter's bed and he started to tell me how he saw the situation.

As this example shows, it may be hard for the nurses/ncas to attend to the patients in a way that fosters 'being with' as described earlier in this thesis (see chapter two). Whilst they are concentrating on providing physical care their attention is focused around doing their task in kind and gentle manner. Therefore they may not notice the signal the patient is giving that he/she is ready and willing to discuss more negative aspects of being ill and nearing death. Furthermore they are looking for a positive outcome from their intervention in terms of making the patient feel comfortable. As described in chapter two 'being with' in facing death is not comfortable, but the notion within palliative care is that this approach is helpful for the patient. By being able to acknowledge the fact that he/she is dying the patient may want to make choices and explore his/her own situation and this was seen by Saunders as a better way to die.

When Audrey was helping Peter he said to her that he did not sleep well. Audrey responded to this in a similarly cheerful manner and said in a light-hearted way, I will cuddle you into the bed after this. She did not ask him why he did not sleep well; she focused on the solution to Peter's sleep problem during the night and said she would tuck him up in bed so he could get to sleep. She focused on something she could say and do that could bring comfort rather than asking Peter why he did not sleep well. However, by doing the latter she might have been able to access some of Peter's perception of his illness, which he had started to share with me when Audrey went away. After she had cleaned Peter she helped him into bed and made him comfortable. When we went out of the room he was looking comfortable and Audrey said to me, 'He is so lovely'. Audrey was kind to Peter and made him comfortable but missed the opportunity to engage with Peter's perception of his situation. In the way the nurses/ncas operated in providing care there was no room for the silence that I provided for Peter, or the availability that indicated that I was ready to discuss with him the more negative aspects of his situation. Maybe it was my silence, maybe my manner, or maybe my facial expression that encouraged him to take the first step in discussing his feelings in relation to the incurable disease he had. Because the nurses/ncas were moving at a certain speed and were busy doing something for the patient, they did not indicate such availability.

The nurses/ncas wanted to be helpful and solve the problems that were causing patients to feel bad. They reduced the discomfort terminal illness caused the patients and managed the negative impact of the disease through physical care. They were preoccupied with doing this in a respectful, kind manner and with showing the patients that they were happy and willing to help them. However in doing so they could not create a situation or an atmosphere that would offer an opportunity for the patient to talk about how he was feeling about being ill and close to death. This was for two reasons. Firstly, with the regime of providing physical care, the tasks involved became the focal point of the nurse/nca's attention. There was much effort involved in carrying out the task in a kind and gentle manner as described in chapter four. Secondly, once the nurses/ncas had completed the required tasks and ensured the patients' physical comfort they did not usually stay with the patients. Nurses/ncas always approached patients with the aim of doing something for them and when they had done that they would leave. They would not sit down with the patient after the physical care was finished, but would go and see the next patient, wander about in the hallway, or sit down in the nursing office and wait for someone needing assistance with physical matters. With this approach the patients knew what the nurses/ncas were available for. They could not expect the nurses/ncas to sit down with them or spend a period of time with them if there was any task needing to be done for the patient. The nurses/ncas' availability was limited to providing physical care which would ensure the patients' comfort.

In chapter four I described how the atmosphere at the hospice was either very busy, energetic and happy, as in the mornings when the nurses/ncas were providing physical care, or very quiet, as the nurses/ncas described it themselves. Over the quiet period there was stillness and silence around the patient but at that time the nurses/ncas would not approach them. They told me that this was the time for the patient to rest or be with their relatives and they would not disturb them. Hence during the quieter time the nurses/ncas did not approach the patients to show that they were available to discuss matters related to their imminent death if they wished to do so. The 'quiet time' was thus not used strategically by the nurses/ncas to provide anything other than physical care.

The patient's rest

The main aim with the care was to solve any problem that was causing discomfort, in a happy, cheerful manner, and once the patient was physically comfortable he/she was left to rest. I was not totally convinced that all the patients wanted to be left to rest during the time the physical care was not happening. For example, once when I was wandering about the hospice during the patients' rest time, I went into one of the ladies' four-bedded rooms where a patient was lying comfortably in her bed. When I walked towards her bed she opened her eyes and I said to her, 'Are you resting?' She said, 'Yes, there is too much rest'. On another occasion I observed Naomi helping a patient turn on to her other side. The patient groaned a bit and Naomi said, 'We will leave you in peace after we have done this'. The patient shouted 'I don't want to be left in peace, I don't want to be left in peace'. Naomi did not respond to this and left the room once she had made the patient physically comfortable. Another time when I was sitting beside Pauline in the conservatory, some of the staff were moving about and at one point took a cushion from one chair and put it onto another.

(1006) Pauline tells me that she is bored. She says, "I am waiting for lunch, that is all you are waiting for. I once worked in a nursing home and I thought 'How can people live for the next meal?' Now I know it is boredom". Some of the staff take cushions out of one chair and put them somewhere else. Pauline looks at them, shakes her head a bit and says in an ironic voice, "They are moving cushions. That is entertaining".

These examples indicate that the rest that the nurses/ncas were so convinced that the patients needed, so that they left them in peace, was not as much appreciated by the patients as they thought it was. The atmosphere that the staff called 'quiet' was for some patients boring. This was indeed what I felt when I came into the hospice at the beginning of my fieldwork. I did not experience the quiet time as peaceful but as boring and lifeless.

The routine and teamwork emphasise availability for physical comfort

In order to manage physical care, the nurses/ncas worked to a certain routine as a team, as described in chapters three and four. As noted, when doing the work the

nurses/ncas seemed to be on a particular track which everyone was expected to be on, moving at a certain speed in order to get things done according to the routine of the hospice. In order to manage this routine, nurse/ncas would always prioritise tasks that needed to be done rather than spend time with a patient who did not require physical attention. The nurses/ncas knew the routine which determined that certain things happened at certain times and they knew they had to follow it. For example, when Nora saw that one of her patients was upset and crying when she was going around in the morning she only attended to her for a couple of minutes and then said to her that she would come back to talk to the patient if she wanted her to. Nora had to attend the planning meeting which only lasted for 5-10 minutes but it was important for her in order to gain insight into matters related to the patients' nursing care. This happened around 9 a.m. I was following Nora throughout the whole morning and after the meeting she did not go back to the patient who had been upset and was crying. She focused on helping other patients in her team with personal hygiene. None of the patients she attended to appeared to be in urgent need of help with physical care, for instance with pain or physical discomfort. The patient, who was crying, on the other hand, did appear to have emotional needs that may have been appropriate for Nora to address. However she focused on helping other patients instead of going back to the patient who was emotionally upset. Hence she prioritised physical care above emotional care for a reason that I could only explain as the ethos of physical comfort above all. It appeared to me that the patient she left that morning was in more urgent need of emotional care than were the patients that she attended to in need of physical care. The nurses/ncas would not weigh up whether the need for emotional care for one patient was greater than a need for physical care of other patients, since physical care always came first. Within this prioritisation emotional care was pushed to one side.

The charge nurse had previously told me that the nurses/ncas would not have time to do 'being with' in terms of sitting with the patient because there were so many things related to physical comfort that the nurses/ncas had to provide. However, in some instances it was rather the prioritisation and the routine that were the controlling factors in what the nurses/ncas did or did not attend to. It would have been possible for Nora to go back after the planning meeting to the patient who was upset. However, it was embedded in the routine she was following that at this time in the morning, nursing care was dedicated to the patients' personal hygiene needs. Usually

that had been finished around 11a.m. and by that time the nurses had other tasks to attend to, for instance, the drug round. If the nurses/ncas did not follow the routine, it might distort the routine of the whole shift. Hence, as noted earlier, it was as if the nurses/ncas were “on a roll” and no one was to diverge from it.

It was evident that the nurses/ncas were expected to help each other carry out the work, and the main workload was caring for the patient’s weak body and minimising the physical discomfort terminal illness caused the patient. There was much effort involved in that and everyone was expected to ‘pull their weight’. It was not well received by the ncas if the nurses did not take a full part in helping with physical care. As Amanda told me when describing how physical care could land on them more than the nurses, ‘It is harder on us than the nurses because it is the staff nurse who is called away and we are left to do the work’ (1012). Maybe Nora was aware of this and felt obliged to pull her weight by providing the physical care so that the ncas working with her in the team would not be ‘left with all the work’, so she pushed the emotional care to one side. She prioritised helping with the physical care of the patients within her team rather than attending to a patient’s emotional distress.

The nurses were usually busy during the mornings attending meetings, helping assist patients with personal hygiene, and attending to physical care-related issues such as pain control. I noted that after everyone had been helped with personal hygiene, ncas would sometimes have ‘free time’. This, however, was never the case with the nurses. They would attend to the drug round and if they were in a more senior position they would also have to attend to the many issues related to being in charge of the ward, as pointed out in chapter four. It is interesting that everyone was expected to help with physical care. Nora, who was an F Grade nurse with various responsibilities, made sure that she was ‘pulling her weight’ in terms of helping the patients with personal hygiene. It was embedded into the routine of the work to meet the aim of having every patient ‘done’ before or around 11a.m.

I also noted that when ncas were less busy, for instance in the late morning and in the afternoon, they did not usually approach the patient in a way that demonstrated that they were available to talk, e.g. by sitting down. They would rather be out in the hallway or sitting in the nursing office ready to respond to the patients’ physical care

needs. There is much effort involved in providing physical care, as shown in chapter two, and once the ncas had done that they could have a little time off. The main workload was done and they could take it a little easier. The hard work period of their shift was over. Perhaps the ncas felt that they deserved the break. After all, they had been working hard for the whole morning. On a few occasions I observed the ncas go into a patient's room when the main workload of physical care had been done. However, in those cases there were usually two ncas together and the way they approached the patient was in the same light, cheerful manner described in chapters three and four. In chapter two I described how Saunders suggested that nurses might show availability for 'being with' in the way I understood it, such as approaching the patient alone, in an unhurried manner and being silent. This I will consider further in chapter eight.

Through the way the ncas approached the patients they showed their availability for social chitchat rather than for a discussion of the patient's emotional state regarding being ill and close to death. For example, once I heard a nursing care assistant remark about another patient, 'I was talking to her but she did not say much. She is not very sociable so I just said, talk to you later'. If the patients did not respond in a 'normal way' to social chitchat the ncas would go away. It was assumed that the patients did not want to engage with the nurses/ncas and were indicating that they should not try to say much or stay with them. However, as described in chapter two, the process of discussing one's own feelings, especially in relation to difficult issues such as terminal illness and imminent death, is a delicate one of showing availability and gently finding out if the patient wants to talk about these things. The ncas did not seem to be aware of this. If the patient was not ready for ordinary social chitchat they took that as an indicator that the patient did not want to engage with them at all. They chatted to the patients in a light, social way but only in the case of Nora did I see a nurse trying to engage with how a patient was feeling in terms of being close to death.

In fact if the ncas had used the quieter time for being available for discussion of the patients' feelings and thoughts about being ill and close to death, it would have been demanding for the ncas, on top of the hard work of caring physically for the patients. Instead of doing that, the ncas had a break in the nursing office chatting to each other or wandering about chatting to the patients in a relaxed and easy manner. They were

also around to respond to issues that arose related to patients' physical care needs. During the observational period there was no evidence of ncas trying to engage with how the patients were feeling regarding to being terminally ill and/or close to death. Nora was the only nurse at the hospice whom I observed trying to engage with a patient's perception of being ill and close to death. She noticed the 'cues' that a patient gave that indicated that she might need to talk about issues related to her illness. However even she did not engage fully with that in the way she responded because she followed the routine and expectations already set at the hospice. Nora²² left the hospice at the end of my data collection.

Although teamwork was a helpful way of organising the care, it could also be an obstacle to individual nurses spending time with a particular patient. The care was organised by a group of nurses/ncas looking after a group of patients. It was not organised to allow one-to-one interactions, and the nurses/ncas were not expected to have long one-to-one interactions with the patients unless they were doing some task for them related to physical care. The way the routine and the teamwork was organised at the hospice was a barrier for nurses like Nora who wanted and were motivated to engage with the patient's emotional state. If a nurse attended to the patient's emotional care, she might 'get stuck' 'being with' one patient and she would disappear from the teamwork and consequently not be able to help with the physical care workload. As I have pointed out, there was not much evidence of nurses spending time with a patient by 'being with' him/her in the sense described in chapter two. However on one occasion Neil had spent some time with Paul, a situation which I did not observe, and when he came back he made excuses to Natalie because in doing so he had opted out of the teamwork.

(1111).

Na: Oh there you are

Ne.: Sorry, I have been with Paul.

Na: Oh I was wondering where you were.

Ne [laughs] Sorry, sorry, sorry, sorry

The nurses were not expected to abandon the teamwork. They had to be available for the nurses/ncas who were working with them and also for other patients. If they

²² Nora might have been in the position that Ryan (1997) describes in his paper, that is when nurses 'go on' a ward they 'join the team' and she might have felt the ambiguity of the dual needs of the patient on the one hand and the requirements of the ward authorities on the other hand.

disappeared and were not performing some task they made excuses for themselves, as in Neil's case. Nora avoided that by attending to patients' physical care needs instead of going back to the patient who was emotionally upset. Nora told me that she was leaving the hospice for a post in palliative care in the community which was in a better location for her because she would be closer to her extended family. She also said with disappointment in her voice, "'being with' doesn't happen that often here' (1303).

The focus of the nursing care was the expectation of providing comfort, and was the main ethos of the nursing care. Hence the nurses/ncas were moving around steadily spotting problems and responding to them. There were problems the disease caused the patient which made him/her uncomfortable unless the nurses/ncas intervened. In order to manage this, the nurses/ncas worked in a certain routine and as part of a team. Everyone took part to sustain this way of caring for the patients. Hence in terms of 'being with' they were 'being around' in order to maintain physical and social comfort rather than 'being with' in terms of showing their willingness to engage with the patients' perception of being ill and close to death. It may be that 'being around' does not demonstrate availability for such a discussion to happen.

In chapter eight I will consider the availability the nurses/ncas showed in their care further by revisiting Saunders' idea of 'being with' in facing death.

Problem-solving mindset

As noted, when providing the care the nurses/ncas always focused on the problem the disease was causing the patient which could threaten the patient's physical comfort. The nurses/ncas provided structured physical care and were 'around' at the hospice making sure that this was managed. This was the driving force of the nursing care and when the nurses/ncas interacted with the patients this 'problem-solving attitude' influenced the interaction. When the patient complained about something that was causing discomfort the nurses/ncas emphasised that there was a solution to the problem and that the patient did not have to be in physical discomfort, rather than

focused on the patient's feelings about the problem. For example, in the extract in chapter five (p.104) Noreen did not aim to hear Pat's perception of being in pain; she emphasised that they could prevent the pain or manage it. She did not give Pat the opportunity to talk about what being in pain might mean for her, or what it might be like to have pain which moves around or to feel you are making progress one day and then going back to square one again the next day. She brought it to Pat's attention that they can control the pain. From this perspective, the hospice exists to serve the patients so they may be in physical comfort so, rather than Pat's feelings, this became the main focus of the discussion between her and Noreen. It became clear that there was something that could be done about the situation and physical comfort was what Noreen could promise Pat. However she did not provide the opportunity for Pat to tell how it felt to be in her situation. What was the meaning of the pain for Pat?, Was she concerned it meant that she was closer to death? Noreen did not seem to think it would be good for Pat to explore this. Physical comfort is the main goal and Noreen interacted with Pat on this basis. I noted that the conversation between Noreen and Pat about the pain lasted only a few minutes and it finished by Noreen giving Pat a painkiller. This happened during the morning when Noreen was busy taking part in the team's routine as described earlier. Noreen would have wanted to say and do something that would solve the problem of pain as she was working in a frame of mind of providing physical comfort. It is also probable that Noreen was aware that she needed to participate in the working routine already established in the hospice to provide physical care for all of the patients. Because of this she focused on the straightforward solution for the pain so she could attend to the next patient or next task. Engaging with how Pat perceived the pain could be more unpredictable. Noreen would not have the same control over what happened as she can have when she focuses on pain management.

As noted in previous chapters the nurses/ncas were in control of the care, followed a certain rhythm that was required, and spotted and solved problems that were usually of a nature that meant they could act immediately. They usually did not have to stop to think or wonder for long about what needed to be done; they did what was necessary without much hesitation. They moved from one task to the next. The nurses/ncas responded immediately to solve what was causing physical discomfort just as Noreen did when she realised that Pat was in pain. Noreen told her that the

solution to the problem of pain was for Pat to let them know as soon as she was in pain, so that they could more easily relieve it. Because physical comfort was the main aim of the care, the nurses/ncas were focused on the straightforward action that they could take to solve the problem, instead of allowing the patient to talk about how it felt to be in this situation. It could be difficult to suddenly change gear from the problem-solving mindset to 'just listen' to the patient and encourage him/her to talk about how he/she perceived the situation. The way the nursing care was organised at the hospice did not encourage such an approach. I noted how this could cause the nurses to focus on solving problems of physical discomfort even when talking to a patient about how he was feeling emotionally.

(1706) Nora is talking to Peter. He is sitting in the living room and facing the window. Nora is kneeling beside his chair so she is face to face with him and she holds his hand. She says "The physiotherapist told me that you did not want to walk today in your walking grid". Peter says, "No I am so tired". "That is fine," says Nora. She asks him how he feels and Peter says, "I am very very tired". Nora asks him "Do you want to go home because you think you will improve there or because you would feel better in your own home? "I do not know. I am confused," says Peter. "Do you think you are like this because of your disease?" Nora asks. Peter says, "Yes". Nora explains to him that if he thinks he might improve by going home that will probably not happen but he might feel better at home, being in his own surroundings. Peter doesn't answer this. Nora asks him "Do you think you are depressed?" Peter does not say anything and Nora says, "It is normal, you have been through a lot. You were disappointed last week because you could not go home". Then she says, "I cannot help but notice your mouth looks dry. Can you show me your tongue?" Peter sticks out his tongue and Nora says, "You have funguses". Then she says, "You thought you might get better after the blood but that has not happened. Do you think you are tired physically or is it your mood?" Peter says "Probably both". Nora says "Do you want me to speak about this to you when your wife is here?" Peter nods and Nora says "I will do that, we have a date then." She stands up and leaves the room.

As I said earlier, Nora was the only nurse I ever observed aiming to engage with how a patient felt about being ill and close to death. In this case she had learned from the physiotherapist that Peter had not wanted to take his usual daily walk through the corridor that morning. The day before he had had a difficult home visit: he could not walk up the stairs and that meant he would not be able to be discharged home. He would die at the hospice. Peter lost his motivation to walk after the home visit. Nora might have guessed this and therefore attended to Peter as he was sitting in a chair in the conservatory. However the interaction with Peter only lasted for a few minutes while Nora asked him many questions and also noticed a physical problem she wanted to deal with. Peter was tired, confused and depressed. In order to be able to

truly engage with how Peter was feeling emotionally, Nora would have had to take a longer time. She was never silent with Peter but asked him many questions. In the state that Peter was in, that might have been rather overwhelming for him. He was starting to realise that he would not be able to be discharged from the hospice. It may be suggested that Nora was rushing Peter rather than remaining alongside him.

Nora was required to be working at the same speed and with the same efficiency as the nurses/ncas, which I have described earlier as being 'on a roll'; a certain rhythm was required that needed a certain speed which everyone had to follow. The nurses/ncas were fast, efficient and confident as they moved about the patients' care and usually helped them by finding a straightforward solution to the problem of discomfort.

Peter was confused and puzzled by the situation. It may well be that by slowing down her pace of work Nora could have engaged with some of Peter's feelings and started to help him to make sense of what was happening. She showed concern for Peter but did not manage to give him an opportunity to talk about his situation. It was mostly Nora who talked; she did not remain silent and only listen, as Saunders suggests might be a helpful approach when enabling patients to come to terms with their own situation of being terminally ill and close to death. It may be concluded that within the rhythm in which the nurses had organised their care it was difficult for them to slow down and be silent. The atmosphere at the hospice, the rhythm of the work, and the expectation of doing something active (as performing a visible task) in order to provide comfort did not encourage the nurses/ncas to just sit with a patient in silence. Hence Nora spent only a few minutes with Peter and during that time she asked him six questions (see p.134) about what he thought about his situation, and also identified physical symptoms that Peter had. Peter showed that he was confused about his situation but did not get much time to think about the questions that Nora asked him.

In chapter four and five I discussed how the nurses/ncas always remained helpful when around the patients. I have also described how the nurses/ncas were always doing something for the patient or saying something that would make the patient feel better. By doing so, they saw the result of their effort in the patient's comfort and I have discussed how this seemed important for the nurses/ncas, namely they where

comforting themselves by being able to comfort the patients. It may be suggested they had to be able to comfort the patients in order to comfort themselves. This became evident, for example, when Nora attended to Pauline who was sitting in a chair in the sitting room and rocking herself backwards and forwards obviously not feeling good. Nora invited her to come with her into a quiet room. When they were in the room Nora asked Pauline what was bothering her.

(2008) Pauline sits on the sofa and Nora sits beside her. Pauline is still rocking as she sits on the sofa. Nora says, "Do you not feel so good today?" Pauline says "No". Nora says "Do you want to talk about what is bothering you?" and again she says, "What is bothering you?" Pauline says "Nothing". Nora asks her again, "What is bothering you?" and Pauline says, "I want to go to bed". Nora says "You obviously are not feeling good today, what is on your mind?" Pauline does not answer and Nora says, "What is happening to you today that makes you feel that way?" Pauline suddenly stands up and says "I am dying, it is as simple as that." Nora asks her "Do you want to go into your room and talk a bit there?" Pauline says "Yes".

When Nora and Pauline came into Pauline's room she said she wanted to get into bed. Nora helped her into her bed. When we were out of the room Nora said to me, 'I didn't think that I did much for her'. She went into the nursing office and was trying to figure out why Pauline was so upset. Nora was obviously concerned. She said to me, 'Maybe it is because she has a fever, she had a fever this morning'. She phoned the doctor who told her that the fever would be tumour fever and would not cause Pauline to be upset. The doctor didn't think there was a reason to do anything about the fever. Nora continued to wonder what could cause Pauline to be so upset and she told me that last evening there were some children visiting the patient in the next bed. Pauline had told the children off for being noisy but afterwards had felt bad about this and asked the nurse on duty to make apologies for her to the patient. 'Maybe that is why she is unsettled today', Nora told me. She was trying to find a reason why Pauline was upset and what she could do to respond to that. She was trying to solve the problem of what was causing Pauline to be in emotional discomfort. It unsettled Nora to see Pauline upset like that and she felt that she had not done much for her. Nora was used to being able to solve the problem of physical discomfort and she was responding to Pauline's emotional discomfort in the same way. She wanted to do something that would solve the problem. Nora dismissed the idea that maybe Pauline had told her what was wrong when she yelled out, 'I am dying, it is as simple as that'.

Nora did not pay attention to that, or dwell on it. Furthermore she felt she had not done much for Pauline and that seemed to make her feel demoralised.

Emotional comfort

Staying away from emotionally difficult issues

The patients at the hospice were in a vulnerable situation which most people would consider difficult; they were terminally ill and close to death. As described in chapter four, the nurses/ncas felt sorry for the patients as they felt what was happening to the patients was sad, and showed concern for them with their kindness and gentle approach. For example, Alicia was helping Patricia to have a bath, when Patricia was trying to stand up from the bath chair and go over to the wheelchair she became tearful. Alicia looked at me with concern in her eyes and then said to Patricia with a kind voice, "If you have pain you don't have to push yourself" (1006). Alicia wanted to prevent Patricia from unnecessary pain. It became evident that the nurses wanted to shield the patients from the pain the disease could cause them. They did so by providing physical care in a kind manner as described in chapters two and three. The nurses went around the hospice in a confident way, knowing what to do to protect the patient from discomfort. Going through the process of getting help with physical care could cause the patient some discomfort, but the nurses/ncas pushed the patient through that in a gentle manner because they knew that it was necessary for the patient and he/she would benefit from it in the end. They were always doing good for the patients. The nurses/ncas wanted to make it more bearable for the patient to be in the situation they were in and the patients benefited from this, e.g. a patient who said to Amanda 'What would I do without you?'

If the patient showed emotional discomfort the nurse/nca wanted to do something that would make the patient feel better. In some instances the kindness and gentleness could include avoiding the issue that was causing the patient emotional discomfort. For example, as I described in chapter five, when Naomi was helping Patricia to have a bath, Patricia started to cry. The situation did not evolve into an opportunity to explore how Patricia saw her situation and what was really worrying her but rather

into an attempt to comfort her by avoiding the issue that was causing emotional discomfort. Patricia gave an emotional signal that she was not feeling good. Naomi noticed that and stopped washing her for a minute and hugged her. She told Patricia that it was alright to cry, but she avoided discussing the issues that were causing her to cry, and she ignored it when Patricia said, 'The doctor made me cry'. In chapter two I discussed how 'cues' should be noticed as signals that patients give which indicate they want to discuss issues related to their illness and imminent death. It was suggested that patients would benefit from being able to explore these issues. Naomi might have been able to engage with what was causing Patricia to be upset if she had explored Patricia's conversation with the doctor. Instead she shifted the conversation away from Patricia's feelings and tried to comfort her by talking about something positive. She also aimed to comfort her by telling her she was going to give her tea and a cigarette after the bath. She showed concern for Patricia and was kind but she did not provide the opportunity for Patricia to express her feelings and thoughts in relation to what was making her upset. She protected Patricia by avoiding the issues that made her emotionally uncomfortable, rather than helping her to confront these as Saunders suggested might be helpful.

'Upbeat' mood

The nurses/ncas tried to make the situation look brighter for the patient by shedding a positive light on it. They would go about providing the care in a happy, confident manner and they were always positive and upbeat when around a patient. In their view, the patients would benefit from that. As the charge nurse told me, 'Otherwise [the patient] will think I must be finding [their situation] awful'. This way of caring for the patient made the atmosphere light and cheerful as described in chapter two. The patients enjoyed this and I saw them laugh and joke with the nurses/ncas. Some of them also told me that the nurses were so friendly and cheery at the hospice and it made them feel good. However I noted that this upbeat and positive approach could cause the nurses/ncas to put such a positive spin on the situation that they missed the opportunity to create a situation for a patient to talk about what she herself felt about her condition. This was the case when I was following Alicia, who was making up a bed in a four-bedded room. Alicia was moving about in her usual cheerful, friendly

manner. None of the patients were in the room. I asked Alicia if Patricia was in the bath and she told me she was sitting in the conservatory. Then she said to me in a happy and slightly unsure voice, 'I wonder if she is from Penicuik?' I followed Alicia as she went into the conservatory and asked Patricia, 'Are you from Penicuik?' Patricia said 'Yes' and Alicia responded by saying in a jolly manner, 'I don't have that bad a memory, then' indicating that she remembered something about Patricia from when she had been in the hospice before. They started to talk about what was happening in Patricia's life when she was at the hospice last time. Alicia remembered that Patricia was doing up her bathroom. Patricia said with disappointment in her voice, 'I did not think I would be back here'. Alicia responds cheerfully, 'Have you not been back since then?' and Patricia replied 'No', with the same disappointed tone in her voice. To come into the hospice means that someone is seriously ill, getting worse and in fact moving closer to death. However the nurses/ncas put a positive spin on the situation and emphasise that the hospice is a good place and that the patients will get help and assistance there. Being very ill is not that bad, as Alicia indicates with her happy voice. She does not pick up the disappointment in Patricia's voice (that may be a cue) or give her a chance to discuss that by, for example, saying, 'Are you disappointed to be back'? Alicia is going about in a cheerful manner and continues in this way when speaking to Patricia, even though Patricia shows signs of disappointment over being at the hospice. By creating a positive mood at the hospice, the nurses seemed unable to be alert when the patient gave a signal that he/she might be wanting or ready to discuss the more negative side of his/her situation.

The nurses/ncas wanted to put an encouraging and optimistic spin on a patient's condition when around them. However, there could be quite a big gap between what the nurses/ncas said to the patient and how they talked between themselves regarding the patient's condition. They would say things about the patient to each other that they would not say to the patient. For example, Nita said in the tape report about Pedro, 'He told me that he was going to fly again someday (Pedro was a pilot). I just nodded'; and then she said in the tape, 'He is going nowhere' (3009). The nurses/ncas were very matter-of-fact and straightforward when they talked about patients' situations among themselves. However, when around the patients they would be upbeat and positive and hold back the more negative views on the patients' condition. For example, when Peter was going for a home visit and was sitting anxiously on his

bed Andrea said to him, 'You will be fine', but in the nursing office she said to Nora, 'He is never going to make it up these stairs'. When around a patient the nurses/ncas were shielding the patient from the negative aspects of his/her situation.

I noted that the nurses/ncas did not seem comfortable about engaging with the patient in a conversation regarding his/her situation if there was a negative aspect to it. They did not enter into the creative process of giving the patient an opportunity to talk about aspects of his/her situation and just see what would happen. The patient might say much or little depending on what he/she was ready for. Such an opportunity could create a situation where the nurse/nca would have had the chance to engage with the patient's experience of being ill and close to death. Nita did not continue the discussion with Pedro, for example, by saying 'Where do you want to fly to? Why do you want to go there?' Because Nita knows that Pedro will die at the hospice, she just nods. She does not want to be cruel to him by saying he will not fly anywhere because he is dying. However Nita did not consider the possibility of engaging in a conversation with Pedro about his desire to fly. If she had, she might have opened up an opportunity for Pedro to share his thoughts/feelings with her. What were his expectations of the future? In a similar way, Andrea did not give Peter a chance to discuss his anxiety and what he was concerned about. By saying, 'You will be fine', she closes the possibility of further discussion about the situation. In both these instances there was something negative that was mentioned. In Nita's case, Pedro says that he wants to fly but she knows he will not. In Andrea's case, Peter is anxious because he wanted to be discharged and the home visit was a trial to see if he would be able to manage at home. If he did not get on well in this home visit he would have to stay at the hospice and he would die there. Because of the comfort-driven ethos of the nursing care neither of them engaged in a discussion about these issues because they both knew that there was something negative involved, something uncomfortable and painful. This involved pain that neither Nita nor Andrea could resolve for the patient. If they had engaged in a discussion about these issues, the patient's pain might have surfaced and they would not be able to do anything it. Another way to look at the situation is that the patient might have benefited from the opportunity of engaging in a conversation with someone about his situation and what he was thinking or feeling, even though there was no solution to his pain. As pointed out in

chapter two, the latter was Saunders' perspective on a better way of caring for dying patients.

The discussion about the more negative side of being ill and close to death was dealt with in these two contradictory ways. On the one hand, the nurses/ncas were upbeat and positive and this could have led to avoiding discussing these issues when around the patients. On the other hand, they were very straightforward when around each other. The nurses/ncas did not seem to engage with the patient's situation. How did he see his situation of being ill and close to death? Such a discussion could be hard for the patient and, as suggested by the literature (see chapter two), also for the nurses/ncas. As discussed in chapter two, from a palliative nursing perspective, the act of engaging with the patients' uncomfortable feelings relating to their illness and death would be justified as doing good based on sensitivity to the patients' needs. According to the palliative care approach symptoms like anxiety would be taken as a cue that it might be beneficial to let the patient know that this anxiety is noticed and for the patient to be able to share the anxiety (see chapter two). In doing so the patient would be given a chance to discuss issues related to the more negative side of his/her illness. He might take the opportunity and he might not. However, the nurses/ncas did not usually create such an opportunity with their approach. They avoided discussing the negative sides of the patient's situation with him/her for reasons which Audrey explained:

You know maybe when they are in their fifties or early sixties and they say I am not getting any better, hen, am I? And you cannot say 'Yes you are', you can not lie. I just close my eyes and put my head down and then they can take what they want from there. And I say 'Would you like to speak to the doctor?', The doctor will tell you what is going on'. Some of them say 'yes' and some of them say 'No hen I am quite content'. You know some of them do not want anything. And ignorance is a blessing, you know, it is lovely, you know, to me, you know, ignorance about lots of things. That is what I think anyway (0212)

I considered the instances when I observed a patient showing signs of emotional discomfort, like a sad face, tears and/or saying something that indicated that he/she did not feel well emotionally, cues that they were needing and wanting to discuss their concerns. However the nurses/ncas at the hospice did not pick these up in the same way as I did. I saw these as an opportunity for the patient and nurse/nca to explore together what he/she was going through in being ill and close to death. However the nurses/ncas missed these opportunities because they either put a positive spin on the

patient's situation or they would avoid issues that were causing the patient to feel bad. It was part of the ethos of the hospice to comfort and to avoid or solve discomfort. It may be suggested that the nurses/ncas at the hospice felt uncomfortable themselves to see patients emotionally upset, as in the extract from my observation (see p.113) when Naomi had helped Patricia with the bath and Patricia was crying. Afterwards when Naomi met Nadia in the hallway she said to her 'Patricia, she is all over the place'. To see patients upset may have caused the nurses/ncas to feel that they had failed in making the patient comfortable, for example, when Angela told me that she had been talking to Prue about how it was in Orkney. She had asked Prue what it was like to teach when Prue suddenly started crying. Angela said to me, 'I thought, oh what have I done? I better not talk about this'. I asked her, 'How did Prue respond when you stopped talking?' Angela said, 'She stopped crying'. I asked Angela, 'Is Prue married?' and Angela said, "I don't know, I did not want to ask her any more of that type question. I did not want to go down that route again' (2307). Angela felt bad when she saw Prue starting to cry as a result of their conversation and she didn't want to upset Prue. It was the opposite of what she wanted to do, i.e. provide comfort.

It also became evident that nurses at the hospice were not comfortable about talking to patients if the patients were angry, or if they had to discuss anxiety, a funeral or a will with the patients. Nora told me how she discovered this at a staff meeting where the nurses were discussing information needed from the patient when he was admitted to the hospice. Nora told me she was surprised to discover this because she considered this as one aspect of palliative care nursing. However as I have formulated in chapter three the nurses/ncas wanted to do good for the patient and they did not see it as good for the patient to cry or talk about distressing thoughts. These issues made them feel ill at ease. They most often avoided such issues or aimed at saying something or doing something that would make the patient comfortable. The nurses/ncas seemed uncomfortable if the patient showed such emotions. They did not consider that emotional discomfort could be a cue signalling that the patient might be ready and/or wanting to discuss issues that were of concern to him/her. They did not seem to believe that the patient would benefit from sharing these issues even if it caused him/her to be emotionally upset when doing so. To see the patient emotionally upset made the nurses/ncas uncomfortable because they felt they were not doing good for the patient.

This made me wonder if they were not familiar with the palliative care approach as described in chapter one. Throughout the observational period there were two nurses that seemed to know about this approach. One of them was Nora (who left the hospice) and the other was Noreen who told me that because this was the 'real world' the hospice ideology was not applicable. They would not have time to carry the ideology out in practice in relation to 'being with'. Hence they had compromised on 'being with' when doing the tasks. Noreen told me that 'being with' would not happen at the hospice, in the sense that the nurses would sit there with a patient, 'because this was all about reality and constraints of the ordinary work' (2101). She told me this referring to the demands and burden of carrying out physical care. She explained to me how they had to be creative at the hospice in relation to providing 'being with' and 'the nurses/ncas would do "being with" by gaining insight into the patient's worries when carrying out the physical care' (2101). With this understanding of 'being with' there is a difference from the understanding of 'being with' as described in chapter two which requires full concentration and a freedom from the distraction of doing a physical task. When observing the nurses/ncas providing the physical care I noted that there were situations where this possibility came up as described in this chapter. However I noted that these usually did not develop into a situation where the patient had an opportunity to share how she/he saw his situation of being ill and close to death. For this to happen the nurses/ncas would have to stop doing the task and focus only on what the patient was saying, which they never did. This might be explained by the roll they were on as noted earlier. Alternatively, the nurses/ncas would have to spend time with the patient after the task was done in order to help him/her to explore further his/her feelings. This again the nurses/ncas never did as noted earlier, since when the task was completed the job was done and the nurse/nca left the patient.

The nurses/ncas were preoccupied with solving problems of discomfort but it also became evident that in terms of emotional discomfort the nurses wanted to say or do something, otherwise they did not consider themselves to be helpful. This became evident when I was following Naomi. One of her patients had died and his relatives were in the relatives' room. She went in to see them but was only in for a few minutes. When she came out I asked her, 'Were they all right'? She said 'Oh yeah,

poor mother she just lost it, and I thought I am just going to cry. I was just losing it too so I just left them. I could not help them, it was not what they needed' (3110). This remark indicates that Naomi didn't think she was helpful because she couldn't do or say anything comforting, neither could she remain upbeat and positive. Therefore the only thing that she could do was to leave. She did not think that she was being helpful or doing any good. The third possibility as suggested by the palliative care approach of 'just being there' and described in chapter two did not seem to be an option for Naomi.

Conclusion

In this chapter I have discussed how the nurses/ncas missed opportunities to engage with what the patient was experiencing in being terminally ill and close to death.

The nurses/ncas dealt with symptoms of emotional discomfort in a same way as they dealt with physical discomfort. They wanted to do something that would make the patient feel better. They wanted to do good and it made them uncomfortable to see the patient in discomfort. Providing comfort was doing good. To encourage the patient to explore issues of emotional distress was not seen as doing good. As described earlier the nurses/ncas did push the patient in terms of physical care. They were able to do something that would relieve the patient of some discomfort when providing the physical care because they knew that the patient would benefit when they had done so, and would be more comfortable than before. This was not the case however, when it came to emotional discomfort. The nurses/ncas seemed to believe that when it came to emotional distress it would be best to try to avoid feelings and thoughts related to this and they distracted the patients from these. The nurses/ncas seemed to be uncomfortable about 'just being with' the patient in the form of just giving the patient opportunity to explore painful emotions and thoughts without doing anything other than listening. In the next chapter I will look at this further in relation to how the nurses/ncas dealt with death.

CHAPTER SEVEN

Dealing with death

Introduction

In previous chapters I have discussed the focus of nursing care on providing comfort and making sure patients were not suffering. The nurses/ ncas managed caring for dying patients by minimising the discomfort terminal illness caused the patients and ensuring their comfort. However, as discussed in chapter five and six, I noted that the nurses/ncas did not engage with the patient's experience of being ill and close to death and the emotions associated with that experience. In this chapter I will look further at this by discussing how the nurses/ncas dealt with the fact that all the patients at the hospice were dying.

Going home or staying

All of the patients at the hospice had incurable illnesses, which on admission to the hospice were causing them some problems, such as pain and physical weakness. This was the reason they were admitted to the hospice. The normal process was that the patient admitted to the hospice had been diagnosed with an incurable disease and as it progressed the patient would gradually become more ill. The disease would cause the patient increasing problems and he/she would become physically weaker and need more and more assistance and help in order to maintain personal hygiene. Furthermore, symptoms of the disease such as pain were likely to increase and the patient would need increasing symptom control management. Patients would be admitted to the hospice in order to get help to manage the problems caused by the disease. How badly patients admitted to the hospice were affected by the disease and how severe their symptoms were could vary. The aim of treating the patient would be to manage their symptoms in order to prevent undue suffering. For some patients it

would be possible to manage the symptoms to the extent that patients would gain some strength back and could be discharged from the hospice. However it was not uncommon that the same patient would be admitted to the hospice several times. Even though it was possible to reverse the situation to help the patient, he/she would most likely have increasing symptoms arising again and would need to be readmitted to the hospice.

When speaking to each other about the patient's situation the nurses/ncas described the patient's condition in terms of whether it would be possible to reverse the situation for the better and if they might be discharged. They would say things like, 'Peter is in for rehabilitation and will go home again, Patricia is having terminal care, Patrick is going to stay with us for the rest of his illness, Paula is going to stay with us' (0905). Sometimes it was not clear whether the patient was going home or whether it would be possible to reverse the situation or not. Concerning these patients they would say, 'He is losing ground, he might go home but he might not' (0905), or 'we are assessing him, we don't know at the moment whether he will go home or not' (1008).

How advanced the disease was for each patient at the hospice was variable. Some of them were more affected by the disease than others. Some of them could be discharged back home, some of them could not. The nurses/ncas would assess the patient in terms of ability of going home as the above account shows.

In some instances it was only possible to reverse the situation to a certain extent, and to get the patient to a stage where he/she was symptom-free. Often the patient was still physically frail and needing assistance at home. In these cases the patient could often still be discharged home but the nurses had to make sure that there would be enough support at home. They would assess his/her needs for assistance at home and the multidisciplinary team would make a decision based on the circumstances. Most often the decision to discharge the patient home was also made with the family and the patient, especially in cases where the patient needed a lot of help at home. In this case the nurses and the doctors would talk to the patient and their family in order to find out if the family was able to care for the patient at home. For example, once when Nora and Doris were having the doctor's meeting, Nora told her that one of their patients would not be able to be discharged home. She told Doris that she had gathered from the family that they would not have been capable of looking after the

patient at home (1706). In many cases a patient needed to receive nursing care at home and also to have an auxiliary device at home and the nurses would arrange this as needed before the patient was discharged home. From the very beginning of the patient's admission there was an ongoing assessment whether the patient was going home or not, as the charge nurse told me:

Interview. Noreen

"[The patients] come to us if they are needing things like increasing physical care and/or symptom control, if they have one or two symptom control issue. And we also get patients admitted for respite and rehabilitation. And a lot of it is about not only dealing with symptom control issues but about what the patients' needs are. Whether they need to get home or in fact want to be home, what is suitable care for them at home, so all sorts of practical issues that we have to negotiate, start looking at".

For many patients it was not clear when they came into the hospice whether they would be discharged or not. The option of discharge was kept open from the very beginning and over a period of days it would become clear if it was possible to reverse the situation for the better. If it was only possible to reverse the situation to a certain extent it was still possible for the patient to be discharged home. The nurses would arrange what was needed at home and the patient would have support from his/her family. In these cases the patient would often have a home visit prior to being discharged to assess how the patients would manage at home. The occupational therapist would go home with the patient and do this assessment. If the home visit went well in terms of the patient managing well in the home, the patient would be discharged a few days later. If this was not the case, the patient might not be discharged.

I noted that there could be much effort involved in planning for patients to go home. There could also be some uncertainty around this issue. In some instances the plan was that the patient would go home and the nurse would spend a reasonable amount of time planning for this outcome. However, if the patient's condition deteriorated he/she would not be able to be discharged home. The situation could possibly change from day to day, hence the situation was constantly being assessed. The effort involved would therefore go towards assessing the situation and trying to figure out what would be possible for the patient. For example, Audrey was once helping a patient to wash. The plan for this patient was to be discharged home. After she had

helped him to wash she gave him his top to put on and said 'I don't want to help you too much, you need to be independent' (0606). She also said to the patient that his wife would need some help at home in order to look after him and they would arrange this before he went home. The patient did not want any assistance at home but had to be convinced that it was necessary for his wife's sake (0606). There was a certain amount of effort that went into helping patients to go back home. Through managing the physical symptoms like pain, and making sure that the patients would get the necessary help at home in order to be able to deal with the demands of home life, the patient could be discharged. When caring for the patients this assessment came to the forefront, the nurses/ncas were continually focusing on whether the patients would be discharged or not and also managing practical things that needed to be done to make this possible. This took up much of the nurses/ncas' time and attention. In some instances the patient went home even though he/she was totally bed-bound and very ill. In these cases the patient wanted to go home and his/her family was ready to look after them. The nurses at the hospice would arrange round-the-clock nursing care at home. However not all of the patients were able to be discharged from the hospice. Patients who could not be discharged were normally very frail and totally bed-bound, and usually very close to death. A few patients could not be discharged due to lack of family support at home.

The situation for all the patients at the hospice was that death was a certainty in the near future. Admission to the hospice would usually mean that the patient was getting more ill. However, the time span from the diagnosis of an incurable disease to death could vary between the patients. For some patients who were admitted to the hospice it would be possible to reverse the situation for the better for a while and they could be discharged home. I noted that being discharged was an important feature of the care for patients as not all patients who came into the hospice would die there, some of them would be discharged. Even though the hospice was a place that patients came to because they were becoming more ill and were in fact moving closer to death, by focusing on the fact that many patients were discharged from the hospice this could be ignored.

Keeping the options open

On two occasions I became aware that home visits that did not go well indicated a turning point for the patient in the likelihood of their being able to be discharged from the hospice. Philip had been at the hospice for two weeks and every day he walked through the corridor in his walking grid. One day he did not want to walk, and had had a bad home visit the day before. Nora went into the sitting room where Philip was sitting in a chair. She told him that she knew that he didn't want to do his walk this morning. Philip looked very disappointed and sad and said that he was tired. Nora told him that he could still go home but she indicated that would be going home on different premises from what he had hoped for. He would not go home because he had the chance of improving but because 'you might feel better, your mood might be better at home, being in your own surroundings might be better' she told him. Philip was confused and did not know what he wanted to do. Nora suggested that she would speak to him again when his wife was with him. Philip agreed to that (1706). Philip did not go home, he stopped walking in the walking grid and he died a few weeks later at the hospice. Nora indicated that going home might be better for Philip, and he might feel better at home even though he would not improve. She was hinting that the home visit signalled that it was not possible to reverse the situation for the better that time; however, he could still go home. On another occasion I observed Nora when she was talking to a patient who had had a bad home visit. Paula had gone home for a home visit with the occupational therapist. When they came back the occupational therapist said that Paula could not be discharged home. I observed Nora discussing this with Paula:

N: I heard you had a difficult home visit

P: Yes I have decided I am not going home, I can not. I have discussed this with my husband and he agrees

N: Yes, but you could also go just for a day

P: I cannot be bothered

N: If you want to go home and sit there and enjoy that you can

P: I can't be bothered

Again Nora is hinting that a bad home visit means that it is not possible to reverse the situation but also that Paula could still go home. When we went out of the room Nora told me that after the home visit Paula got much worse physically and she thinks that

it might have been her low spirits after the home visit that were causing her to feel bad. She told me that she was wondering if Paula could still go home and said, 'I don't want to close the options like that'. Generally speaking a bad home visit did indicate that the patient could not be discharged from the hospice, he/she was not able to manage at home. Not being able to go home meant that the patient would die at the hospice. I noted that even though bad home visits were a clear indication that the patient had moved closer towards death, which in a way was a significant turning point, in neither case did Nora ask the patient about his/her feelings related to this matter. Rather than focusing the attention on the fact that this meant that the patient would be staying at the hospice and discussing the patient's feelings in relation to that, she pointed out that the patient could still go home. She emphasised that going home was still an option rather than engaging with the patient in conversation about what this turning point meant for him/her. Both of these patients died at the hospice.

The focus of the nursing care was around planning home visits, and planning for being discharged from the hospice. I never saw a nurse/ncs drawing a patient into discussion about the turning point when it became clear that he/she would probably not be discharged and how she/he felt about that. By focusing on the fact that the patient could be discharged from the hospice the nurses/ncs could downplay the fact that being admitted to the hospice did mean that the patient was moving closer to death. When talking to each other about the patients the nurses/ncs would state quite clearly what the situation was with the patients, i.e. he/she was either going to be discharged or would be staying at the hospice. However they would not discuss this as clearly when around the patients and home was kept open as an option for every patient. All the patients at the hospice were on a journey from the diagnosis of having an incurable disease that would gradually lead to their death. However even though most of the patients admitted to the hospice were expected to die within six to twelve months there was some uncertainty when exactly this would happen. The nurses/ncs anticipated how close to death the patients were by considering whether the patients were going home or not and informed each other about the patients' situations. However this information would not be passed on to the patients. Around the patient the nurses/ncs would not usually engage with the patients about the fact that he/she might possibly be staying at the hospice which meant that they were very close to death. The nurses/ncs overplayed the fact that the patient might have the possibility

of being discharged home. Keeping the option of going home open did take the focus off the fact that the patients came into the hospice because they were moving closer to death.

Home is better

The option of going home was kept open as long as possible for the patient. Going home was better. It meant that it was possible to reverse the situation, to move away from a place where people died. It also meant more power for the patients to do what they wanted to do. Nora tells me about Prue who had been in the hospice for a few weeks. Prue showed that she was unhappy at the hospice. She was often restless and walked about in the hallway in an angry state. Nora told me 'I have doubts whether we are meeting all her needs, you know you should be able to look back and see that we have met her needs'. Nora told me that other members in the team thought that Prue could not be discharged home because she lived on her own and would not have enough support at home. Nora did not agree with this and said, 'You know it would have been more for her [at home]. She could have done what she likes, you know she sometimes likes to walk around naked'. Nora raised her hands in frustration and said, 'At least she could have done that' (2008). Nora's remark supports what I observed during my fieldwork that there was not much that the patient could do at the hospice in order to maintain the life they used to live. Patients at the hospice were usually lying in their beds, most often sleeping or lying half-asleep. They were frail and tired. If patients had the energy to be up and about they would be discharged home. It was the patients who were most ill and closest to death that stayed at the hospice. In that sense the hospice was a place for people to die in, it was for the patients who were closest to death, patients who had moved to the end of their journey. However, a few patients less affected by the disease stayed at the hospice for a longer period because like Prue they could not be discharged home due to lack of support from family to care for them. The nurses/ncas thought that the hospice did not have much to offer these patients, as Nora was indicating when she told me about Prue.

Paul was also a patient who had been at the hospice for an unusually long time. Paul was not able to be discharged home, as he needed some assistance and support that

was not available from family. However he was not as close to death as many of the other patients who were staying at the hospice until they died. Paul also indicated that he was unhappy at the hospice. Angela told me that Paul most often had his eyes closed and did not show any interest in anything. 'It is his mood, I think', she said. 'It would be better if he could go out for a bit, it would lift his spirit but the weather is not good enough', she told me with sadness in her voice (0406). When I asked Paul how he was feeling he said to me, 'Not well, the sooner I get from here the better' (1706). Paul died at the hospice a few weeks later. The remark from Nora and Angela shows that they felt helpless in terms of doing something that would make Prue and Paul feel better. On another occasion when Nora was in the nursing office talking to the doctor about four patients who were all very close to death, she said with a gloomy voice, 'They all want to die'. The doctor said 'Yes and what we want to do we can't'.

The hospice is a place to die in

For the patients who were at the hospice to stay, it was not possible to reverse the situation for the better and the patients had reached a point where they were expected to die within a few days. In this respect, the hospice was a place where patients died, and as Nora's and the doctor's remarks show, this could contribute towards a depressing atmosphere. However, when around the patients the nurses/ncas tried to overcome this with cheerful and helpful attitudes as described in previous chapters. What they could do for the patients was to ensure their comfort. Nevertheless it was not possible to cure the patient and both the nurses/ncas and the patients knew this.

Through the data collection I became aware that when it became apparent that a patient would not be able to be discharged and he/she would die at the hospice, the patient and his/her family were informed about this. On two occasions I heard the doctor and nurses speak at the doctor's meeting about the patient and family having been informed of this, i.e. they knew what the situation was (1006, 2705). On another occasion at the doctor's meeting, a daughter of one of the patients who was close to death was mentioned and the doctor asked 'Does she know?' The nurse answered, 'Yes she knows'. However when I was observing at the hospice I never saw this

discussion take place. Furthermore, as pointed out in chapter two, 'being with' in facing death based on Saunders' writings facilitates the journey of moving from intellectual knowledge of death to emotional acceptance. For Saunders, intellectually knowing was different from emotionally accepting that death is near. The patients at the hospice seemed to know of death but they were not encouraged to undertake the journey that Saunders believed was vital in order to die a good death.

During the observation I became very aware that discharging home was an option as this was discussed in a great detail with the patient, and I often became aware of the nurses attending to this either in discussion with the patient or by preparing for a home visit. In contrast, the turning point of not being discharged did not get as much attention. On one occasion I heard the doctor telling the nurse that he had been talking to a patient about future possibilities. This patient was moving closer towards death and had had severe difficulties with coping at home before admission. Later the patient was crying and said, 'The doctor made me cry'. The evidence I have indicates that informing the patient about the turning point was done by the doctor. The nurses/ncas did not seem to have the confidence to discuss the patients' imminent death with them. For example, Audrey told me that she found it difficult if patients asked her directly what the situation was with them and if this happened she would invite them to speak to the doctor. 'They say "I am not getting any better, hen, am I?"' And I say, "Would you like to speak to the doctor? The doctor will tell you what is going on"'. On another occasion Nora was speaking to a patient who was upset and doubting if the chemotherapy she had been receiving had been any help (1711):

P: I am worried about the chemotherapy, it makes me feel very sick and not any better.

N: But they are reducing the dose now, the doctor needs to discuss this with you.

The patient indicates that she is worried because the chemotherapy is not working. Nora indicates the solution to that i.e. the chemotherapy has been reduced. However that also means that it is not working, and the patient will not be cured with that therapy. She does not engage in discussion about this but refers it to the doctor. On another occasion I observed Nora talking to Prue where it came up that she was very close to death. Nora was asking her why she did not feel well that day, what was bothering her. Prue did not give an answer to this but Nora tried to push for an answer

by asking several times, 'What is bothering you?' In the end Prue yelled out 'I am dying, it is as simple as that'. In a way it was simple: every patient who had to stay at the hospice and could not be discharged home would die very soon. Everyone knew that. The patients knew it and the nurses/ncas knew it. The nurses/ncas would have liked to be able to see the patients cured but that was not an option and the patients knew it as well. They knew providing comfort was what could be offered to them at the hospice, and the nurses/ncas were doing the best they could. Both patients and nurses/ncas were aware of the fact that the patients were dying and the nurses/ncas would not be able to do anything to achieve a more positive outcome despite wanting to be able to do so. It was self-evident that every patient at the hospice was dying, and there was nothing anyone could do to prevent that.

However, as pointed out in chapter two, death was not simple in Saunders' eyes. It was an opportunity for personal growth, healing of relationships and preparation for death. The nurses/ncas in M Hospice did not seem to share Saunders' view that by facing death, it could be turned into an opportunity rather than defeat.

Hiding death

Despite the fact that death was known to happen in the hospice, I noted that the staff considered that the sight of patients who were close to death would be disturbing for the patients who were not as close to death. For example, on one occasion the doctor was talking to Nora about a patient that he wanted to admit to the hospice. He explained that the patient had been managing at home but she was in increasing pain and needed to be admitted for pain management. Then he said to Nora 'She is much better than them here, it might freak her out to see them'. I noted that the nurses were concerned about how the sight of death and dying would affect the other patients. For example, when I was following Nora, when she was nursing Paula who was very close to death, Nora was considering whether she should move Paula into a single room. She was wondering how it would influence the other patients in the room to see someone so close to death. Paula was in a four-bedded room. She told me that the decision was a bit of a dilemma for her.

(1706) I wonder if I should move Paula, because I think the other ladies are watching her, especially Petra (at the doctor's meeting earlier that morning Nora had told the doctor that Petra was anxious). But Paula is well aware of what is happening in the surroundings even though she does not respond much but she moves her eyes when you talk to her. What will she feel if she is moved to a single room? And how will the other [patients in the room] feel if she just disappears from the room? But it will be more space for her relatives if we move her. I am just going to think this through the day and see what is best to do.

Next day I asked Nora what she did and she told me that she did move Paula to a single room, and Paula died soon after that. Nora told me, 'Her husband was upset so it was better for him to be in privacy and also for the other patients'. This account from Nora shows that from her perspective it was better for the other patients that Paula was moved away so they would not see death happening. Seeing someone else die might make them anxious. Nora said to me that she told the other patients that Petra was poorly and that was the reason why they had moved her. However it appeared that the patients knew that moving her into a single room meant that she was dying. Nora told me that when they were moving her she could hear one of the patients saying to the relatives that were visiting her, 'I am not ready for that room yet'. Nora told me that the patients call the single room the 'departure room'. The term used in this way by patients has a slightly humorous tone. However Nora said to me 'Isn't that horrible?' She said, 'It must be difficult for them, I mean, it does remind them of their own mortality' (1806). This remark from Nora indicates that to be reminded of one's own mortality was something awful. She did not see it as an opportunity as Saunders did (see chapter two). This will be discussed further in chapter seven.

I have previously pointed out that when I came into the hospice I would not have realized that death happened nearly every day in that setting. The light, cheery atmosphere the nurses/ncas created was apparent most of the time even when someone had died. The nurses/ncas moved about in their usual happy, helpful manner carrying out the routine tasks at the hospice. The sight and notion of death as part of day-to-day life in the hospice was hidden away from the patients as much as possible. Normally it was not evident from the atmosphere that the death of a patient happened frequently at the hospice. If it were, it could be worrying for the staff because they were thinking about the other patients who were also close to death and how it would affect them to see or sense death in the atmosphere. The nurses/ncas tried to avoid

reminding or confronting the patients with the fact that they were close to death. The nurses/ncas cared for these patients in a happy and gentle manner until the patient died, and protected them from having to confront their own mortality. Encouraging someone to confront his/her own immediate death was not seen as helpful. For example, when Prue yelled out 'I am dying', Nora asked her if she wanted to go back into her room, although they were sitting in the 'quiet room' having this conversation. Prue said 'Yes' and Nora took her into her room. Afterwards Nora said to me with a sad voice, 'I did not think I did much for her'. According to Saunders' belief (see chapter two), Nora was perhaps getting to the bottom of Prue's anxiety, and this might be beneficial for Prue to explore through talking about it.

It was recognised that the patients who could not be discharged home were dying and it would not be possible to reverse the situation. The time was running out for these patients. It appeared that at this stage what the nurses/ncas could do for the patient was to keep him/her comfortable. In this sense death was taken for granted, everyone knew that would be the outcome for the patient but it was not discussed. What it meant for the patient to be close to death was not discussed. Providing comfort was the nurses/ncas' tool when caring for the patients and that was what they could provide at the hospice. The patients were grateful for this and it gave the nurses/ncas job satisfaction to be able to ensure the patients' comfort; it was the measure of a good job done and this was what they were accountable for. The fact that the patient was moving towards death was taken for granted, and the nurses/ncas knew this but avoided raising the issue. In chapter six I discussed how the nurses/ncas missed opportunities to discuss what it meant for the patient to be ill and close to death because they did not pay attention to the patient's cues regarding this issue. They were preoccupied with making the patient comfortable. Engaging with one's own mortality and the fact that the patient was close to death would cause some discomfort and this was avoided by the nurses/ncas. Staying in the hospice was for patients who were coming to the end of their journey. For these patients the hospice proved to be a safe and comfortable environment in which to die. Most of the patients died peacefully. If they still had some time still to live they would be discharged home or to a nursing home.

Anticipating death

All the patients at the hospice were going to die in the near future; there was no uncertainty about that. The question was when the patient was going to die. All of the patients were on the journey from terminal illness to death. The nurses/ncas anticipated how close to death the patient was by categorising the patient's situation by either their going home or staying at the hospice. Not being able to be discharged meant in most cases that the patient was very close to death. When this had been identified, the nurses/ncas switched from assessing the patient in terms of whether he/she would be able to be discharged to assessing the patient in terms of how close to death he/she was. They anticipated when exactly the patient would die. For example, they would describe the patients as 'not dying in the next weeks' (1405) or 'she is dying now' (1006). In some cases there was more uncertainty and the nurses/ncas were not quite sure how close to death the patients were and whether they would go home or not. They would discuss these patients in terms such as, 'We are assessing him, we don't know at the moment if he will go home or not' (1008). These two things, i.e. how close to death the patient was and if he/she would go home or not, were the main issues that were looked at in light of the fact that all the patients were dying. The expectations were that the patient would either be dying soon or would be able to be discharged home and this was the focus of attention in terms of the patient's situation. The focus of nursing care was not on what it meant for the patient to be very close to death or how he/she perceived his/her situation. The focus was on when the patient was going to die and where.

All the patients were close to death, so the nurses/ncas expected the patients to die and, as discussed in the previous chapter it was the ultimate solution. The nurses/ncas did not usually express any discomfort over the fact that the patients would die soon when they discussed the patients' situation with each other. The nurses/ncas would state the situation with the patient as a matter of fact, namely how close to death they were and the possibilities of being able to go home. When someone died the nurses/ncas usually continued the work in their usual manner and followed their set routine. The death of a patient did usually not cause them to be upset, nor did they discuss this matter at any length. However on one occasion the death of a patient caused the nursing managers and the nurse who was on duty when the patient died to

reflect on what had happened. This was on morning duty and the patient had died on the evening shift the day before. The patient's death was not expected that soon, even though the patient had been close to death like all patients at the hospice. The managers sat down for about ten minutes with Natalie, who was the nurse on duty that evening, because they wanted to know how she felt about the incident. She told the managers what had happened. The patient had suddenly got breathless and restless. His family was with him and he died half an hour later. Natalie gave the patient sedative drugs but did not make any attempt to save the patient from dying and she told the managers that where she had been working before (in an intensive care situation) she would have responded differently (1610):

N: I would have phoned 999 and all that stuff

M: Yes it is very different here but you did everything right

N: I said to the family 'Do you want me to stay?' and then I was hoping they would say no but they said yes and to be honest I did not want to be there but I just sat with them. You know he was just similar age to my husband, and his son kissed him and said 'I love you dad'. I think he tried to say 'I love you back' at least that is what I thought he was saying. I had tears in my eyes I could not say if [the family] have seen I was upset.

M: That is ok, you did not lose yourself, you stayed calm, collected and confident and they have sensed that.

N: I felt so helpless, I wasn't really doing anything

M: You did the right thing, you stayed with them

This was the only occasion when I was aware of a nurse who had stayed with a patient and his family while the patient was dying. It was unusual at the hospice for a patient to die as suddenly as this. Usually the patient would gradually fade away. The nurses/ncas could anticipate what was happening and usually the patient's family would expect it as well. The nurses/ncas could often predict if the patient would die on their shift. In this case Natalie did not know that this was happening. She felt bad because she did not do anything; however she also knew that within the hospice setting a nurse is not meant to try to save a patient from dying. Usually the nurses/ncas would inform each other through the taped report if a patient was very close to death and the nurse/nca on duty could prepare herself for this eventuality. However this had not been the case in this situation and that had made Natalie feel insecure about it. She was not prepared for the outcome in that timescale. On another occasion Amanda told me that she was affected by a patient's death. She found it stressful to discover when she arrived at a morning shift that a patient she had been nursing on a late shift the day before had died during the night. She told me:

I spent some time chatting to this gentleman, passing him a phone message, transferring phone calls for him and I came in the next morning and he had died during the night and I really could not believe it but it was so sudden and unexpected.

Death was not usually sudden or unexpected at the hospice because the nurses/ncas were informed of how close to death the patient was. Usually the nurses/ncas had followed the process of seeing the patients getting weaker and weaker as they were moving towards death. By assessing the patients and informing each other how close to death they were, the nurses/ncas could prepare themselves for the death of patients. They would notice the progression that usually happened over the period of a few days. The nurses could assess how close to death the patient was by looking at the patient's symptoms from the disease and by informing each other of these signs. They would say, for example, 'It looks to me that he has lost ground a bit, to me he looks thinner, paler' (1706) or 'She looks very frail now' (1706). The nurses/ncas would prepare themselves for the death of a patient by anticipating when the patient would die and informing each other about that.

Coping with death

Death was expected to happen at the hospice and the fact that someone had died at the hospice usually did not affect the staff in a way that was noticeable in their day-to-day practice. However, when I talked to Alda in private she did show how it affected her when one of the patients had died that day:

(0110) Alda and I are having a chat in one of the patients' room but there are no patients there at the moment. At one point Alda looks at the bed that is empty. Her eyes fill with tears. She says "I am looking at this bed. Paul was there, the undertakers have just come to take him, he was playing golf only 6 weeks ago, he is younger than my daughter". She cries a bit and then she says, "You have to vent it out". I ask her what she normally does to vent it out. She tells me "We do that with each other here. Ann and I go out in the car and have a cigarette and a chat".

This account from Alda indicates that there was not a place within the hospice where they could 'vent things out'. There was no formal forum or place for the nurses/ncas to discuss how they felt about working somewhere where death was a frequent

occurrence. Audrey told me that she would go away for a few minutes either to the toilet or to the changing room which was on the third floor of the building to have a few minutes on her own to compose herself. This was most likely to happen when there had been many deaths over a short period of time (0212).

On one occasion I noticed that Audrey was affected by the many deaths that had occurred within a short time.

(2207) Audrey comes into the coffee room, she looks tired. She sits down and says, "I was with the undertakers". Nurses and ncas who have been sitting in the coffee room go out of the room; the break time is over for them but Audrey says, "I am going to take my ½ hour ". She says to me, "I did not want to come in this morning". She tells me that she has handed over 4 bodies to the undertakers over a short period of time.

When I asked one of the nursing care assistants how she coped with the fact that so many of the patients died at the hospice, she told me that when she goes home she switches off.

Interview Alicia

A: You can not take everything home or you would be a wreck. I mean because we go through that many [deaths] some days. And I mean sometimes there are so many in a week that we just could not possibly... nobody could do that and handle it. You must switch off. I think there must be a switch [laughs] to switch off.

I: Yes there are large numbers of deaths in here, even 2-3 per week.

A: Aha, sometimes you can have six in two days or even eight in two days. I mean, if you didn't switch off you wouldn't be anything, I think.

This remark from Alicia shows that she protected herself from the stress of seeing many patients die by 'switching off'. She tried to forget all about the work situation when she is at home. However she also admitted that sometimes she would suddenly wake up in the middle of the night and start to think about some of the patients (0212). Alda told me that she had been working at the hospice for 25 years and said, 'You never get used to [the deaths]'. She explained that some situations are more difficult than others, for example, a 39 year old man who had a brain tumour. She said he is married and has two children, and as she said this she raised her hand and shook her head. She told me that being around him is difficult and sometimes she needs to go away and do something else like unpacking a suitcase or going and chatting with the other patients and joking with them (1906). She told me how important it is to have

patients with whom you can just chat and joke. 'It is a cover-up but I don't know how else I could cope' (1906).

I noted that humour was a way to cope with the frequent deaths at the hospice. The staff made jokes between themselves about death. Once when I was in the coffee room a few of the nurses/ncas were there for their break. Audrey came into the room and said, 'I was with the undertakers'. This triggered off a discussion about jokes that have been made through the years relating to death. Audrey told how she was teasing one doctor when he went down where the bodies are kept. She lay down under a sheet and stood up as he came in. 'He was so shocked that it took him a long time to recover', she said, and everyone in the coffee room laughed. Natasha said, 'It is so necessary to laugh and make jokes about death. It relieves the tension. When I started here six years ago I found this kind of talk outrageous'. When the nurses/ncas were around the patients they did not make jokes about death even though they were interacting with the patients in a light and cheerful manner as described before. However on one occasion a patient made a joke himself about his own death. When I introduced myself to Peter and told him I was doing research and would be around at the hospice for the next 3-6 months, Peter laughed and said to me, 'I will be frozen then'. Audrey was with me and we both laughed as well. When we were out of the room in the hallway Audrey started to laugh again and said, 'That was so funny' (2205). Next day I was shadowing Audrey and she told Nara what Peter had said yesterday. Nara smiled and Audrey said to both of us, 'I found it so funny'. She also told Noreen, who turned round to me and said, 'So you are learning about the culture here?' (2305)

All patients at the hospice were going to die soon, but this was not noticeable in the day-to-day atmosphere. The only occasion when I observed the nurses discussing a patient's death was when that had happened unexpectedly. When speaking to the ncas they told me that it was when death happened unexpectedly or there had been many deaths over a short period of space that they were affected. They would show their reaction either by going away in private or by talking to each other. There was no time or space set aside for the nurses/ncas where they were expected to reflect on patients' deaths. The nurses/ncas dealt with the frequent deaths by talking to each other outside the hospice, going away for a few minutes, joking and chatting to the

patients who were less affected by illness, joking to each other about death and trying to avoid thinking about work at home.

Conclusion

I have described above how the nurses/ncas talked about the patients' immediate deaths between themselves in terms of how close to death the patients were and where they would die. They were focusing on practical issues that needed to be arranged in terms of where the patients would die, and by being informed about when the patients would die they were preparing for that eventuality. It seemed that if it happened this way it affected them less than if they were unprepared for the patient's death. I noted that death and dying were usually not spoken about openly when nurses/ncas were around the patients, so death was hidden away from the day-to-day environment.

I noted that there were two ways the nurses/nca dealt with the fact that all patients at the hospice were close to death. Firstly, when they were around the patients they avoided the discussion and were upbeat and positive as described in previous chapters. This atmosphere offered the patients a way of protecting themselves from the fact that they were getting closer to death. Secondly, when around each other they were very matter-of-fact about death. They would make statements about the patients' imminent deaths in short sentences like 'He is dying now'. This would not be discussed further and everyone knew what it meant. Patients at that stage were cared for in the manner described earlier (see chapters four, five and six). Death was the end goal, it was expected to happen and as such was taken for granted. The journey that Saunders believed was necessary for a good death did not take place. Death was known in the hospice but not emotionally accepted. This is what this thesis now turns to consider.

CHAPTER EIGHT

'Being with' as comfort and 'being with' in facing death

Introduction

This study is an exploration of how 'being with' happens in day-to-day nursing practice within a hospice. As a palliative care specialist prior to doing this study I had an idea of what 'being with' was, based on my own practice as shown in the introduction. The way I understood the concept before data collection was based on Saunders' notion of 'being with' in facing death (see chapter two). I became interested in trying to explicitly formulate how this happened in practice through personal observation. As the reader has discovered, 'being with' in facing death did not happen in nursing practice where I did my study in the way I had expected, based on Saunders' notion (as formulated in chapter two).

When observing how 'being with' happens in everyday practice I had to suspend my own formulation of 'being with' in facing death (see chapter three), otherwise I would only have seen 'being with' as absent from the nursing practice in the hospice where I did my study. Based on my observation and analysis, I formulated the nurses/ncas' understanding of the concept 'being with' in relation to providing comfort. Constructing 'being with' as providing comfort meant a certain behaviour and attitude that was generally demonstrated by the nurses/ncas as shown in chapters four, five and six. Furthermore, this behaviour and attitude actually hindered an open awareness of death rather than encouraging the patient to face his/her own imminent death. My own understanding of 'being with' was challenged by understanding the way the nurses/ncas had constructed the phenomenon in their daily practice. As a result of this I became more critical of Saunders' notion of 'being with' in facing death. In this chapter I will discuss the key differences between Saunders' approach towards caring for dying patients (that I have formulated as 'being with' in facing death, see chapter

two) and the nurses/ncas' approach (that I formulated as 'being with' as providing comfort, see chapter five). This will highlight how the nurses/ncas' construction of their work demonstrated an absence of the phenomenon 'being with' in facing death. Furthermore, it will also highlight the constraints of the environment and the culture at M Hospice, that is the constraints of the 'ordinary' work in relation to doing 'being with' in facing death. This will also draw attention to the ideological status of Saunders' work and the barriers that may hinder day-to-day practice reflecting her ideology.

In this chapter I will also continue to consider the denial of death 'thesis' (already discussed in chapter two) but now in relation to the findings of this study. I will offer a further critical review of Saunders' notion of facing death by considering the attitudes the nurses/ncas at M Hospice had towards death and dying. I will draw on Heidegger's work in reflecting on Saunders' ideology of facing death and offer a critical account of her philosophy that further helped me to understand why 'being with' in facing death was absent from nursing care at M hospice.

The structure of the nursing care as a barrier against 'being with' in facing death

Routine and availability

As I have shown in previous chapters the nurses/ncas were busy due to all the demands involved in the physical care of the dying patient. Most of the patients at the hospice were physically frail and needed lots of assistance. This was why they had been admitted to the hospice and it manifested itself in nursing care that was built around this need and was organised in a firm routine and teamwork. This caused a certain rhythm in the care that everyone followed in order to make the system of caring for dying patients work as shown in chapters four and five. Things were done at a certain time and this kept the nurse/ncas busy. However, I propose that it was not only due to busyness that 'being with' in facing death was absent in the nursing care at M Hospice but also due to the way the nursing care was constructed. In the

way the nurses/ncas had constructed the care, they did not demonstrate that they were available to do 'being with' in facing death. This was accepted by the patients.

I have described in previous chapters the way the nurses/ncas had constructed the care through a set routine and a manner that demonstrated busyness. They moved in a fast, deliberate manner but attending to everything that needed to be done based on routine. Even though they were gentle when performing the tasks and took the time that was needed, it was obvious that they had much to do. As pointed out in chapter four, the patients picked up this busyness and they could easily see that the nurses/ncas had a clear agenda for their shift. The nurses/ncas also made it apparent that they had time and were available for the tasks and for which they were responsible. These tasks were mostly related to physical care that ensured comfort. They would leave the patients immediately after the task was done. Furthermore, the teamwork and routine did not allow for any deviation from the way nursing care was constructed.

As stated in chapter two, according to Saunders, availability in the form of showing that one has time for one-to-one interactions is necessary for 'being with' to happen when close to death. Saunders gives an example of a patient whom she helped to face death who...

*... confided in [her] because she approached her alone and not in a hurry
(Saunders 1959 p. 11).*

Saunders believed that health care professionals who showed their availability to discuss issues related to impending death would be successful in helping dying patients face death. However her suggestion that the nurses/ncas could show their availability for 'being with' in facing death by approaching the patients 'alone and not in a hurry' did not fit into the care in the way it was organised within the hospice. The team worked together in a certain style that everyone was supposed to follow in order for the work to be done. There was a rhythm and a style of work that everyone had to adapt to; it was an established rule that none of the nursing team was supposed to break (see chapter four). Approaching the patients in the way that Saunders suggested would have broken the rules and disturbed the routine of the work that ensured, as the nurses/ncas saw it, appropriate allocation of tasks and a fair sharing of the work load. Tasks were shared out in a systematic way and all nurses/ncas were

expected to get these done within a certain time frame and this ensured a fair workload and smooth routine. These were embedded rules that everyone took for granted and hence were invisible to the nurses/ncas, but which became apparent if someone broke this rule. For example, the student nurse who I referred to in chapter five obviously had a different manner from all the other staff. She moved slowly which irritated the nurses who doubted that she would make it as a nurse, as she would not be able to get her tasks done. The nurses in the hospice questioned whether this student nurse would be able to cope with the demands of the job once she had graduated, due to her slow manner²³. However, according to Saunders, by her unhurried manner she was showing the availability that was necessary for 'being with' to happen when close to death.

In reflecting upon Saunders' suggestion in the light of my data, I wonder whether she underestimated the demands the physical care of dying patient would impose on nurses and the structure that may be needed to ensure physical comfort for all patients. It also made me think that it is possible that the demands of physical care are still underestimated in palliative nursing.²⁴ Furthermore, Saunders believed that nurses were well placed to provide 'being with' in facing death and that they could be in a position to encourage the patients to take on the painful journey of travelling towards the 'moment of truth' (see chapter two). In the light of my data, I now consider that this might be difficult to achieve in addition to the other responsibilities nurses have when nursing care is structured in the way it was at M Hospice. The 'moment of truth' that Saunders referred to is not easily defined in her writings. She also claimed that true facing of death could not be done once and for all. It would take time and be done bit by bit, as patients would need to have a break from facing their difficult situations. As noted in chapter two, Saunders believed that encouraging the patient to express and share the painful truth of his/her situation should only be done if the patient showed signs of willingness to do so and this is now widely recognised within palliative care practice as 'cues'. This means that the nurses/ncas would have to be able to recognise when the patient was ready to undertake this journey, and

²³ Melia (1982) in her study of nursing students found that student nurses experienced this on some of the wards they did their training on. Sitting and talking to patients was not seen as proper work and in doing so they risked being seen as not pulling their weight.

²⁴ It has been pointed out that physical care within nursing is taken for granted and hidden see Lawer (1991).

engage with them if they were ready but also know when he/she wanted to avoid the issue. I realised if the nurses/ncas at M Hospice were to do 'being with' in facing death they would have been faced with a challenge that had not been highlighted to me before. They would have to be ready to engage with the patient at a level where he/she could connect with the truth of the situation, while also offering the patient a break from this if he/she so wishes and on top of that providing the demanding physical care as described in previous chapters. If the patient was ready they would have to engage with them on an emotional level but the way the care was organised at the hospice did not allow for this 'time out' from the routine. The way the nursing care was constructed at M Hospice did not allow 'space' for this to take place due to the busy rhythm and style of the care. The structure of the care did not allow any room for this engagement to take place. If the nurses/ncas picked up signals from the patient that they might be ready to discuss their illness and own imminent death, they would break the routine.

Even though Saunders (1959) acknowledged that knowing when a patient was ready for 'being with' in facing death might be difficult, she didn't offer any practical ways as to how the nurses/ncas could meet the challenges discussed above. When stating that nurses would be well placed to provide the aspect of care that includes 'being with' in facing death, she never highlighted the problem that 'being with' in facing death does in fact not lend itself to a firm structure. Doing 'being with' in facing death (see chapter two) can not be boxed into a particular time during the nurses/ncas shifts like other aspects of the care and this of course imposes challenges on nurses who have to construct some structure in order to ensure comfort for all patients.

The nurses/ncas at M Hospice did not do 'being with' in facing death due to the way they had structured their work through teamwork and routine. Environmental and cultural barriers, related to the way the nurses/ncas had constructed their work as described in chapter four, made it difficult for the nurses to show the availability that is necessary for 'being with' to happen when facing death. However it should not be denied that in the way the nurses/ncas had constructed the care they provided excellent physical care and provided an environment that was friendly and comfortable.

'Being with' in facing death requires certain availability by the nurses/ncas and this was not part of the day-to-day nursing practice at M hospice. The care was structured and routinised in a way that made it difficult for nurses/ncas to demonstrate such availability to their patients. May (1995) suggests that 'being with' is a different type of undertaking from what nurses are used to doing when the focus is on physical care. For 'being with' to happen the nurse needs to shift his/her attention in order to be able to interact with the patient. May (1995) describes this as availability rather than action. May (1995 p.560) describes how listening requires

...the nurse [to arrange] her work in a way that makes it possible to speak, and to be willing to participate in the encounter.

Perhaps it was very difficult for the nurse/nca to shift their attention into 'mood' of 'being with' in facing death. That required them to slow down and be silent and listen in a culture that emphasised care that needed to follow a certain routine and rhythm.

The notion that 'being with' is embedded into the physical care

The nurses/ncas had constructed 'being with' as providing comfort rather than facing death so they did not think that anything was missing from their care (even though they were not available for 'being with' in facing death). As a group, the nurses/ncas had established that the care they provided was adequate care, for them it was palliative care. This meant that no one felt there was a need to critically look at how the care was organised. When I spoke to the charge nurse (G-grade nurse) about the possible lack of 'being with' in facing death, she told me that because of the demands of the physical care, the nurses/ncas provided 'being with' at the same time as physical care. However, 'being with' in facing death would not be possible to do at the same time as physical care. The activity of 'being with' (as shown in chapter two), would absorb all the attention of the nurses/ncas. It would not be possible for them to show the kind of availability Saunders suggested when they were doing tasks for the patients. The nurses/ncas would have to approach the patient alone and unhurriedly to show that they were available and had time for an interaction such as 'being with' in facing death. In contrast, the nurses/ncas with their focus on the physical care effectively showed the patients that getting the tasks done was the main agenda in their interaction with them and the patients were compliant in that. 'Being with' as

comfort can be incorporated into physical care as has been shown in this thesis, but 'being with' in facing death can not be done at the same time as physical care is provided. My study supports the general claim that attending to a patient's physical care can trigger 'being with' in facing death. That is, the patient will start a conversation related to his/her perception of his/her illness when the nurse/ncs is providing physical care. However, to address this issue the nurse/ncs would have to stop doing their task and focus only on what the patient was expressing. The way the nurses/ncs had constructed their care did not allow this to happen. The nurses/ncs would always continue with their task and their main focus would be on physical care even when the patient raised some uncomfortable feelings related to their illness. Furthermore, the nurses/ncs always left the patient immediately after the task was done even though the patients showed or expressed any difficult feelings. As noted they would offer quick reassurance rather than engage with the patients' feelings. I felt the charge nurse was confusing the two concepts of 'being with' in providing comfort and 'being with' in facing death by stating that the nurses/ncs would do 'being with' as incorporated into the physical care. Field (1989) points out the ward sister is the one who influences whether 'being with' patient in order to provide emotional care is accepted on the ward as part of the daily routine. It is interesting that the charge nurse who was a specialist palliative care nurse had the view that "being with' in providing comfort would be a substitute for 'being with' in facing death. According to Field's (1989) study this would influence the perception of the nursing staff on the ward as to what was acceptable care.

Tradition

M Hospice had been a nursing home prior to becoming a hospice. Even though many new staff had been employed at the hospice, including the medical director, nursing manager, charge nurse, F grade nurse and staff nurses, some of the staff who had worked at the hospice when it had been a nursing home were still there. It is possible that the way the nursing care was constructed had followed on from the nursing home regime. However, it is also interesting that despite all the palliative care specialists who were employed at the hospice the shift to specialist palliative care in relation to 'being with' in facing death had not been made within the nursing care. Field (1989) points out that traditional nursing care is organized in a routine way and in a

predictable manner so nursing staff can cope with the demands that are placed upon them. Individual personal needs of patients may be overlooked in the pursuit of these routines. Saunders, with the hospice movement, aimed to offer dying patients 'holistic care' of dying patients' (social, physical, psychological and spiritual) in order to meet individual needs of patients. Unlike hospitals hospices accepted emotional involvement as a natural and important part of the relationship between caregivers and those who were dying, and provided a support system to enable their staff to cope with the involvement (Field 1989). For the palliative care approach to be adopted into a nursing care environment where nursing care is structured in a traditional way may be hard since it demands less routine and structure to the care. At M Hospice there was a tension between how 'being with' in facing death demonstrates itself and the way the nursing care was constructed. Saunders believed that day-to-day nursing could provide the opportunity to encourage patients to undertake the journey from an intellectual knowledge of death to an emotional acceptance. However as I have discussed in this section, in order to do this the structure of how the nursing care is traditionally constructed may need to be altered in order to accommodate 'being with' in facing death.

Teamwork

In previous chapters I have discussed that the nurses and especially the senior nurses had various duties to attend to whereas the main duties of the nursing care assistants were to assist the patients with their personal hygiene. Despite various duties the nurses would always make sure that they would take part in the daily routine of helping patients to maintain their personal hygiene. As noted in chapter six there was some indication that the nurses were under pressure to take part in the physical care so the nursing care assistants would not be left alone to attend to this task that was seen as very demanding. It was not viewed in good light if the nurses 'disappeared' from helping the team providing the physical care and if they did not do their bit so the routine would be kept. The nursing care assistants complained if the nurses would not take part in this activity because it was seen as the main work. Even though the nurses/ncas told me that they would all accept that someone was sitting and talking with a patient their behaviour and attitude proved contradictory. Everyone was meant to pull their weight in the already set routine and not disturb it. In this respect, the

teamwork and the culture of helping each other with the demands of the work was a barrier to the nurses doing 'being with' in facing death.

Despite Saunders' belief that nurses were well placed to provide 'being with' in facing death I did not see this happen in the nursing care at M Hospice during the 9 months of my observation. In chapter six I discussed how I noticed signs given by patients that I interpreted as their readiness/willingness to discuss more difficult aspects of their situation more often than the nurses at M hospice. Whether the nurses were ignorant of the signs or chose to ignore them I am not sure. What is clear is that environmental factors and the culture of M Hospice did not allow the nurses to engage on this level even though they would have liked to as in Nora's case. (See chapter six). In an environment where there were implicit rules that everyone was expected to pull their weight in relation to providing physical care, it was difficult for the nurses to 'disappear' from the teamwork. This might be the one reason why they did not notice the cues from the patients or paid little attention to them offering reassurance rather than facilitating an expression of emotion. As Field (1989 p.32) points out

The nursing care which people in our hospitals receive is not simply the product of decisions and actions of individual nurses.

This was very evident in M hospice. The nursing care in M Hospice was constructed in a way that allowed for 'being with' in providing comfort to happen but not 'being with' in facing death. Furthermore, it also made the nurses/ncas able to provide what they called palliative care without noticing that something was missing from their care. The nursing staff were confident that what they were providing was a specialist palliative care style of nursing care. Despite the fact that there was no evidence of emotional care in relation to the patients who were close to death, they felt nothing was missing from their care. Everyone, including the senior staff who seemed to have knowledge of the palliative care approach accepted this apart from Nora (one of the team leader) who left the hospice while I was nearing the end of the data collection.

Providing comfort as part of palliative nursing

The concept of comfort is seen as closely linked to palliative nursing and where nurses claim that they make a specific contribution (Seymour 2004). However comfort is not only seen as an aspect of palliative nursing but also within nursing in general and is well recognised as a goal of good nursing care. Despite this, the concept is neither clearly defined in nursing literature (Malinowski A and Stamler L (2002), Tutton E and Seers K (2003) Tutton E and Seers K (2004) Siefert ML (2002)) nor is it analysed in literature as how to comfort makes a specific contribution to palliative nursing (Seymour 2004). What was evident at M Hospice was that the concept comfort was demonstrated through what I have formulated as 'being with' in providing comfort. Furthermore, the way the nurses/ncas had constructed 'being with' as comfort was problematic in terms of allowing for 'being with' to happen in facing death. Instead of engaging with dying patients' painful feelings, the nurses/ncas would provide comfort through excellent physical care and minimising patients' suffering through symptom control and a friendly atmosphere. However as Seymour (2004) point out, comfort within palliative care practice may go beyond the physical and social comfort the nurses/ncas in M Hospice provided.

My study suggests that the concept of comfort has complex meaning and this may be true especially in palliative nursing that stresses the importance of the inclusion of the expression of painful feelings. As will be stated later in this chapter emotional comfort may be hard to achieve when a patient is facing death. It is anxiety provoking and emotionally distressing to face death and this poses challenged on nurses/ncas providing the care. There is no 'quick fix' solution applicable in order to relieve the anxiety or distress. According to Saunders one needs to 'go through' the painful emotions in order to find relief. When it comes to emotional suffering it is not possible to say or do anything to alleviate the suffering as a 'quick fix' in the way physical suffering can be solved.

I noticed that the nurses/ncas at M Hospice always approached the patients with a mindset of what they could do for them. As shown in examples in chapters five and six, nurses/ncas felt bad unless they had done something practical for the patient.

They were working within a framework of doing things for patients, solving problems, and as a result, making patients comfortable. Doing something for the patients meant they had 'done good' for them. 'Being with' as facing death may be difficult to do within a culture that emphasises that 'doing good' is to do something for the patients where problems are solved. 'Being with' in facing death does not lend itself to such an approach; it is not a work that is very visible and does not have any obvious outcome. 'Being with' in facing death may be sidelined within nursing care where the meaning of the care is related to doing something for the patient, making him/her comfortable and with immediate results.

When developing strategies to relieve suffering, Saunders differentiated between the relief of physical suffering and emotional suffering. In regards to emotional suffering there was nothing practically to be done to alleviate the suffering apart from listening to the patients. This would involve a passive act rather than an active intervention which might be very difficult in essence for nurses/ncas in a 'doing-for' driven culture. Saunders suggested with her work that a patient who was experiencing emotional suffering needed 'being with' in facing death rather than 'being with' as providing comfort (as the nurses/ncas at M Hospice had constructed the concept) because he/she should be encouraged to confront their own death. This was, in her eyes, the solution to the suffering and would in the end ensure emotional comfort. The nurses/ncas at M Hospice did not seem to share Saunders' belief that emotional suffering could eventually lead to emotional comfort if it was allowed to be expressed and explored. Hence, if the patient showed signs of emotional discomfort like sadness, crying or distress the nurses/ncas used the same approach as they did when providing physical care. They would try to alleviate the suffering by saying or doing something that would immediately bring comfort rather than encouraging the patient to go through the suffering by 'being with' in the way Saunders understood it.

On the other hand I noticed how the nurses/ncas were actually ready to push the patient through a certain amount of discomfort related to physical care in order for the patients to be physically comfortable as a result of the care. For example, it might be uncomfortable for the patient to have a clean sheet put on his/her bed, when the old one was wet and/or dirty as this would have to be done with the patient in the bed. However the nurses/ncas knew that putting the patient through this discomfort would enhance his/her comfort in the end more than if it were avoided. When it came to

emotional care they did not believe in the same way that some emotional suffering would be necessary to ensure emotional comfort. They would never encourage the patients to go through the pain of expressing and exploring feelings related to death and dying (as Saunders suggested) but rather try to distract them from it, as shown in previous chapters. The nurses/ncas at M Hospice did not share Saunders' view that there would be some positive meaning related to allowing emotional pain to be expressed and experienced. However this would be necessary for them to be able to do 'being with'. They would have to share the same attitude towards suffering as Saunders did. They would have to believe they were 'doing good' even though the patient was suffering emotionally, furthermore they would have to allow themselves to be with the patient when there was no obvious task to do for the patient. As noted this was not the way the nursing care was constructed at M Hospice. Hence, the painful emotions that are eventually associated with death and dying were excluded from reality in the hospice setting. This was done by constructing 'being with' as providing comfort rather facing death.

Seymour (2004) points out that relieving distress and providing emotional comfort in the case of severe emotional or existential distress rests on the understanding that relief is possible. The nurses/ncas did not seem to have the understanding that emotional pain related to death and dying could be relieved by expressing it and exploring. They wanted to protect the patients from facing death. When the nurses/ncas were around the patients they created an atmosphere that was light-hearted and cheerful as described earlier in this thesis. Because they had adopted this approach in their busyness and their manner, they did not appear brisk or harsh even though they were moving in a fast and focused way. Even though getting the tasks done was the main focus of the care, it was done in a light-hearted which showed that the nurses/ncas were happy to help. This atmosphere was comfortable, however this did not encourage or facilitate 'being with' in facing death to happen. This raises the question whether all the patients at the hospice were truly comforted.

Being kind and providing reassurance

Saunders suggested a fine balance between a joyful and cheery atmosphere that would bring comfort and an approach that would encourage the patients to face death. She

did not advocate an approach that encouraged patients to face death to be demonstrated all the time for every patient. She believed that some patients would not be willing at any time to face the truth of the situation and when this was the case, health care professionals should respect this wish (Saunders 1959). As discussed in chapter two it would be the patient who would decide when and if he/she was ready. Saunders also believed that it would be necessary for patients to have 'a day off from truth' (Saunders 1984 p. 297). Saunders believed that when interacting with dying patients, glossing over the painful reality of the situation would be appropriate on some occasions in order to comfort the patient. However there would be times when encouraging the patients to undertake the journey from intellectual knowledge of death to an emotional acceptance was more appropriate than glossing over it. For Saunders, the light and cheerful atmosphere was a proper atmosphere to create around dying patients but only when they needed the comfort from this approach. Such an atmosphere would not facilitate 'being with' in facing death, but on the contrary, would encourage a break from facing death.

A happy and cheerful atmosphere was the dominant atmosphere within M Hospice (see chapters four and five). It was a distraction from a distressing situation that might be hard to face; it was an attempt to avoid a painful truth, namely, that the patient was dying. The nurses/ncas created this atmosphere through their energetic busyness, humorous comments, laughter, pop music and light chit chat. In the afternoon they would encourage a quiet atmosphere when the patients were resting (as the nurses/ncas saw it). If the patient looked physically comfortable he/she was not disturbed. As noted this was 'being with' as providing comfort but it was not 'being with' in facing death. It was an attempt to gloss over the knowledge of death rather than encourage patients to undertake the journey from 'knowing of death' to an emotional acceptance of death that Saunders believed would be helpful for many dying patients.

For Saunders kindness was a delicate process of finding out what dying patient needed and wanted to know and/or explore in terms of their own situation

I think it is rarely right for us to take the initiative and even when we are asked we must sometimes hedge and prevaricate where we judge the patients to be unready as yet to face the full knowledge. Those who establish close contact with

their patients will best be able to decide whether they want or need to be enlightened and will approach as friends with courtesy and kindness (Saunders 1959 p.9).

Saunders believed that the patient's need to undertake the painful journey towards emotional acceptance would become apparent to the practitioners who were willing to watch the patient closely.

It is people and the look on their faces that matters, because from the look on their faces we learn both their needs and their achievements (Saunders 1969 p.52.).

As stated earlier the structure of the nursing care at M Hospice did not allow for 'watching the patient closely' in relation to his/her emotional state. In fact the atmosphere that the nurses/ncas had constructed discouraged difficult emotions from being expressed and explored, as for them, this would ensure the patient's comfort. Instead of facilitating the expression, of emotions the nurses/ncas would try to reassure the patient that everything would be fine. Saunders believed that reassurance was a technique to avoid having to discuss the painful issue of being terminally ill and close to death.

Now we can be reassuring about it all. If we refuse to discuss it openly, or smother their questions in a kind of blanket of reassurance, they still know very well what is happening. What we have said to them, in effect is, "I am afraid to discuss it". They want to talk about the other questions [related to their imminent death] and they will do it when they are ready if only we let them" (Saunders 1969 p. 61-62).

What was apparent to me was that the nurses/ncas at M Hospice did not provide the opportunity for patient to undertake the emotional journey of accepting death because they demonstrated kindness differently to the way Saunders discussed kindness. By their approach, they precluded the opportunity for 'being with' happening in facing death. By their kind and gentle approach and by creating a cheery and happy atmosphere they provided reassurance that for them would ensure comfort. However, according to Saunders for some patients a different approach, namely 'being with' in facing death would be more appropriate.

As discussed in chapter two, Aranda (2004) refers to Street's (1995) work when using the term the 'tyranny of niceness' to describe one aspect of stress for nurses in

palliative care. Street (1995) uses this term to describe a culture that involves being nice, not making a fuss and smiling a lot, even though that goes against one's real emotional state. Someone might go away from someone whom they had been 'nice' to and complain about him/ her behind their back. Hence, the term is used for covering up one's true thoughts or feelings. In my own study it was apparent that the nurses/ncas' were covering up sad emotions in relation to death and dying by being nice and creating an atmosphere that would cover up for the fact that death was imminent for all patient at the hospice. This was accepted in this environment and overall, the nurses/ncas wanted to care for the patients in the way they did and on most occasions they actually liked being nice to the patients. This gave them purpose and meaning in their work. It was part of 'being with' as ensuring comfort, and usually the patients showed their gratitude which meant a lot to the nurses/ncas. However, I also noticed that the nurses/ncas used this 'niceness' to preclude any sad or difficult emotions in relation to the fact that all patients at the hospice were dying. As described in earlier chapters this was helpful to a certain extent for patient and for the nurses/ncas themselves in order to cope with what was happening. I also noticed that it encouraged an avoidance of the expression of true emotions in relation to death and dying that according to Saunders thought would be helpful for some patients to be able to express at times. Because of the way the care was constructed, the conditions for happening were not created by the nurses/ncas. If the patient demonstrated that he/she was ready and willing to 'be with' in facing death by showing signals such as a verbal 'cue' and/or facial expression the nurse/ncas did not pick up on these signals. The opportunity for 'being with' in facing death was squeezed out by providing comfort. This was demonstrated by the nurses/ncas being kind and keeping a light and, sometimes, quiet atmosphere. What is questionable though is whether this approach ensured emotional comfort for all patients. As noted, I observed that some patients indicated that they were bored and fed up, and some expressed distress that was not picked up by the nurses/ncas. According to Saunders, suppressing feelings related to one's illness and imminent death would not ensure emotional comfort. On the contrary only by expressing and exploring these feelings would the patient be truly comforted. The patients at M Hospice were encouraged to suppress their feelings related to their illness and imminent death if these were painful. For the patients who were ready to exploring their emotional distress, (and according to Saunders would have benefited from the experience) different strategies were needed in the care then

what had been adopted at M hospice. Instead of addressing the patient's emotional/existential distress the nurses/ncas dismissed signals from their patients that indicated readiness to explore their own feelings. The nurse/ncas were always gentle and kind to the patients, but what was lacking was true engagement with what the patients were experiencing.

Protecting the patients

As described in chapter four, the nurses/ncas seemed to pity the patients, as was evident in the way they spoke about them to me and between themselves. This also became apparent through the soft voice and childlike communication they used when talking to the patients. It was clear that the nurses/ncas thought of the patients' situation as horrendous. The nurses/ncas, quite realistically, saw the patients as vulnerable and in a difficult situation. The nurses were there to help the patients and minimise their suffering with their kindness, gentleness and reassurance as discussed above. The patients' weak bodies and lack of physical ability might have encouraged a perception that they were fragile, and sometimes this may have led to the overprotection that appeared in the parent/child quality of relationship between the nurse/ncas and the patients. Seeing the patient in a childlike way may have encouraged a protective approach when it came to issues in relation to the patient's death. However, Saunders with her notion of 'being with' in facing death warned health care professionals against an overprotective approach.

We tend to look at [the dying patients] with that pity that is not so far removed from contempt (Saunders 1965a p. 70).

Saunders suggests that health care professionals should not try to shield patients from emotional suffering. Instead patients should be encouraged to share their experiences and for, Saunders, that was 'being with'. Approaching the patients alone and without hurry would foster this and encourage patients to alleviate their suffering by exploring the feelings and issues that were causing them emotional pain. Saunders called this a 'matter of fact' approach towards what patients were expressing rather than feeling sorry for them. Emotional suffering is overcome by going through it, by having someone to listen and by being able to express the emotional pain and issues that are causing the distress. Perhaps the nurses/ncas saw themselves as cruel if they would

foster an expression of difficult feelings because they saw the patients as weak or vulnerable and needing protection. In some ways they did, as shown in chapter five. Hence, the nursing care at the hospice was organised around patients' needs and the vulnerability they were experiencing. The nurses/ncas perceived the patients as vulnerable and responded with the reassurance that they would minimise their suffering. The nurses/ncas did not focus on the patients' strength and courage as Saunders had advised.

By reflecting on Saunders philosophy, being informed by my study, I consider that perhaps it is under-estimated how difficult it actually is for nurses/ncas to be with patient in their emotional suffering. As noted in chapter two, 'being with' as an approach in assisting patients to disclose difficult emotional issues was discussed in an ideological way by Saunders and this is often the case in nursing literature as well. Staying with patient in their emotional suffering is emotionally demanding for nurses/ncas. Literature on 'being with' dismisses this very often by discussing the concept of 'being with' in ideological and an abstract way. The constraints of the ordinary work is not taken into account as well as not taking into consideration the support that the nurses required in order to be able to offer this type of care. Perhaps by constructing comfort in the way the nurses/ncas did (through exclusion of all suffering, including emotional suffering) the nurses/ncas were comforting themselves but believed that they were comforting the patients. Again in this situation patient were compliant to this notion. Perhaps this was the nurses/ncas' only way to cope with the demands of their work.

Death as the ultimate comfort provider

As shown in chapter seven, for the nurses/ncas it was death itself that would bring comfort. Their perception of being close to death was that it was bad and they pitied the patients who were facing death. As noted they did not believe that encouraging the patients to go through the suffering by expressing and exploring their painful feelings would bring relief. On the other hand, being dead was not bad and that was in fact the solution to their patients suffering. The strategy the nurses/ncas employed in making death and dying more bearable was to do 'being with' in providing comfort. They did not use Saunders' strategies of encouraging patients to face death and to use the time

that they had left to confront death, prepare for it and finish their own life in an individual based way. Even though some patients indicated that they were distressed, Saunders strategies for helping to relieve suffering by expressing emotions were not applied. It appeared to me that the nurses/ncas were waiting for death rather than encouraging the patients to actively use the time that was still left, even though this might be emotionally painful. As shown in chapter seven, in order to manage death the nurses/ncas at M Hospice used the strategy of anticipating when the patient would die. However, they would never disclose their own thoughts about this to the patients, even if the patients signalled that they were ready and willing to engage into such a conversation. If the patient did not die when expected it caused surprise and staff became puzzled. The way the nurses/ncas at M Hospice dealt with death was by predicting when it would happen even though this would be kept from the patient. In this sense they prepared themselves for the patients' death but did not encourage the patient to prepare for it. This enabled a perception of death in a matter of fact and simple way; every patient in the hospice was expected to die. The nurses/ncas were more surprised if the patients did not die than if they did die because death was expected.

Lawton (2000) in an ethnographic study in a hospice in England showed that patients who didn't die broke the norm and upset the routine. She claims that being available for a patient who did not die when they were expected to die was too demanding for the staff. She describes how a number of hospice patients experienced 'social death' especially in the case of older people. In a case study Lawton (2000) discusses how staff at the hospice failed to provide a 'temporary surrogate family' and 'safe haven' for one of these patients. This, she suggests, increased the patient's sense of sadness and abandonment; the staff and family in the situation got confused and withdrew because the patient did not die as quickly as was expected.

My own findings suggest that patients who did not die quickly in M Hospice did not die socially before they died physically due to 'being with' as providing the comfort that was practised in the hospice. However I would suggest that some of them died emotionally before they died physically. These are the patients who I gave examples of in the previous chapter who showed signs that they were willing or, according to Saunders, needing to undertake the emotional journey that she described. They might

have benefited from that. For example, Peter told me that he had cancer which was moving about, but did not get the opportunity to express his concerns. Petra told me that now all she could do was wait for the next meal. I had noticed how she was struggling to do the simplest tasks in relation to her own personal hygiene but was reassured that she did not have to bother as the nurses/ncas would do it for her. I also noticed how she tried to express her concerns but was reassured by the nurse changing the topic and offering her a cup of tea. Paul stopped walking in the corridor because he had lost motivation and hope after a bad home visit. He knew he would die in the hospice and it made him anxious and puzzled. These patients I believe would have benefited from Saunders' approach of 'being with' in facing death.

Facing death

As noted, Saunders philosophy was a reaction towards the isolation of dying patients within the health care system that became evident in the late 1950's and 1960s. She aimed at changing health care professionals' attitudes towards death that were coloured by fear and by feelings of helplessness when around dying patients. This caused patients who were dying to feel abandoned. She aspired to encourage a more open discussion of death and dying. Saunders philosophy is highly recognised as underpinning the modern palliative nursing practice but this aspect of her philosophy had not been translated into the day-to-day nursing practice at M hospice. The nurses/ncas had constructed a care that made them able to interact with dying patients in a way that enabled them to manage the care and ensured their own comfort, namely by excluding the fact that all patients at the hospice were close to death.

Heidegger's (1962) theory of facing death highlights the problem that human beings have in relation to facing death. From his existential standpoint he believed that human beings or *Dasein* do not have the capability to interpret the phenomenon of death in order to incorporate the experience into their own existence because once *Dasein* has experienced death, *Dasein* is dead. However *Dasein* has the potential to interpret and understand the phenomenon *anticipating the possibility of death as certain* and by doing so it becomes incorporated into *Dasein*.

Being-towards-death, as anticipation of possibility, is what first makes this possibility possible, and sets it free as possibility (Heidegger 1962 p. 307).

Saunders' notion of 'being with' in facing death and Heidegger's theory of how humans can face death have something in common. Saunders believed that death could bring something good for the patient if he/she were encouraged to go through the suffering entailed in facing death and which echoes Heidegger's thinking in regard to how death can bring something positive into people's lives if it is anticipated as a certainty. For Heidegger (1962), despite the fact that death ends one's existence it was a fundamental phenomenon for existence. If *Dasein* faces its own death by anticipating it this has positive implications in an ontological sense. Death marks *Dasein*'s existence in a way that enables *Dasein* to become aware of its own existence in an authentic way.

Being- towards-death is the anticipation of a potentiality-for-Being of that entity whose kind of Being is anticipation itself. In the anticipatory revealing of this potentiality-for-being, Dasein discloses itself to itself as regards its uttermost possibility. But to project itself on its ownmost potentiality-for-Being means to be able to understand itself in the Being of the entity so revealed - namely, to exist. Anticipation turns out to be the possibility of understanding one's ownmost and uttermost potentiality-for-Being-that is to say, the possibility of authentic existence. The ontological constitution of such existence must be made visible by setting forth the concrete structure of anticipation of death (Heidegger 1962 p. 307).

For both Saunders and Heidegger, facing death served an important purpose for human beings, namely that recognising that one's life was coming to an end brought the possibility of authenticity or personal growth.

For Heidegger, as long as *Dasein* exists it is always moving towards something that is 'ahead of itself', there is always something 'outstanding' and something more to come.

In Dasein there is always something still outstanding, which, as a potentiality - for-Being for Dasein itself, has not yet become 'actual' (Heidegger 1962 p 279).

Death completes the picture for *Dasein*. It is not until death that the possibility of something ahead has gone. Hence by acknowledging death in an ontological way, one

recognises that time for something more is limited and this fosters authentic existence as people are stimulated to be proactive in trying to complete their own life.

Death and anxiety

Even though that both Heidegger and Saunders believed that death could be a positive phenomenon in the way it is described above, they both acknowledged that facing death would be a painful experience. For Heidegger (1962) anticipating the possibility of death as a certainty enables *Dasein* to aim for the uttermost possibility of its existence, although this manifests itself in anxiety.

Being towards this possibility [of death] enables Dasein to understand that giving itself up impends for it as the uttermost possibility of its existence (Heidegger 1962 p. 308).

In anticipating the indefinite certainty of death, Dasein opens itself to a constant threat arising out of its own "there". In this very threat Being-towards-the-end must maintain itself (Heidegger 1962 p.310).

But the state-of-mind which can hold open the utter and constant threat to itself arising from Dasein's ownmost individualized Being, is anxiety. In this state-of-mind, Dasein finds itself face to face with the "nothing" of the possible impossibility of its existence. Anxiety is anxious about the potentiality-for-being of the entity so destined, and in this way it discloses the uttermost possibility. Anticipation utterly individualises Dasein, and allows it, in this individualisation of itself, to become certain of the totality of its potentiality-for-Being. For this reason, anxiety as a basic state-of-mind belongs to such a self-understanding of Dasein on the basis of Dasein itself. Being-towards-death is essentially anxiety. (Heidegger 1962 p.310)

Anticipating the possibility of death as a certainty brings on anxiety. In accordance with Heideggerian thinking, anxiety for *Dasein* is anxiety over knowing that its existence is coming to an end. Saunders also acknowledged that facing death would be associated with anxiety but she describes that as emotional suffering. As already noted, for Saunders believed that 'being with' in facing death did not have the purpose of eliminating the suffering but of accompanying the person in their journey towards death. Saunders believed that when actually facing death, a patient would suffer. This is also similar to Heidegger's belief that anxiety was a state of mind for 'being towards death'. For Saunders, suffering in this sense was not bad for the patient; it was a necessary part of facing death and enabled the patient to move from intellectual knowledge about death to an emotional acceptance that would foster the

patient's ability to complete their own life. Hence for both Saunders and Heidegger 'being towards death' is a painful existence; however both believed that this pain had a purpose because it would lead to a good death for Saunders and an authentic way of being for Heidegger (1962).

The notion of good death

I have discussed how engaging with a dying patient's painful emotions is part of 'being with' in facing death. Within palliative care literature the claim is made that ever since the hospice movement was established, emotional involvement with the dying person has been acknowledged as a vital component of good care. This encourages an open awareness of the patient's impending death and leads to a 'good death' (Copp 1997, Boyle and Carter 1998). However, as demonstrated both by Heidegger and Saunders this would involve anxiety. In the palliative care literature it stressed widely that dying patients should be encouraged to face death. By reflecting critically on Saunders notion with' (being informed by my research and Heidegger's theory of the anxiety that facing death provokes) ,it became apparent to me that there are no practical outworking demonstrated in the literature as to how such a goal can be met. What is evident is that by practising an open awareness of death and allowing death to surface into the atmosphere of M Hospice the nurses/ncas would have risked disturbing the structure and routine within the care that they believed ensured comfort to so many patients. In previous chapters I have discussed how death did not disturb the work of the nurses/ncas. They would keep their structure and happy atmosphere that made the hospice comfortable to stay in and this was without doubt good for many of the patients who stayed at the hospice. Aries (1974) argues that the reason for death denial is that death causes "disturbance". Death usually provokes strong and unbearable emotions caused by the ugliness of dying and interrupts the pleasant rhythm of social life. Furthermore Seale (1998) points out that physiological denial of death may be necessary for normal functioning of individuals within a society.

Sociologically, death poses problems at two levels: for the stability of social structures, and for the maintenance of individual meanings that sustain ontological security (p. 50)

On the other hand Saunders believed addressing the fear of death would actually be necessary for many patients and she suggested that health care professionals should encourage an attitude of facing death when the patients gave signals that this was what they wanted and/or needed to do. Heidegger's (1962) theory of facing death highlights that because facing death causes disturbance to social life, 'being with' in facing death is not possible. He believed that one person would never encourage another to face death. For Heidegger, 'being with' in facing death in the way Saunders described it (for one person to be present to another to encourage expression of emotion around death and dying) would not happen. On the contrary, facing death would only be possible through being alone and not with other people.

The ownmost possibility is non-relational. Anticipation allows Dasein to understand that that potentiality-for-being in which its ownmost Being is an issue, must be taken over by Dasein alone. Death does not just 'belong' to one's own Dasein in an undifferentiated way; death lays claim to it as an individual Dasein. The non-relational character of death, as understood in anticipation, individualises Dasein down to itself (Heidegger 1962 p 308).

In Heidegger's view, humans do not anticipate death as a certainty because of the way the phenomenon is dealt with in the world. This is due to the way *Dasein* publicly interprets the phenomenon death:

The foundation of any interpretation is an act of understanding, which is always accompanied by a state-of-mind, or, in other words, which has a mood. So we must ask how Being-towards-death is disclosed by the kind of understanding which, with its state-of-mind, lurks in the idle talk of the "they". What state-of-mind discloses to the "they" that it has been delivered over to death, and in what way? The "they" has already stowed away an interpretation for this event. In Dasein's public way of interpreting, it is said that "one dies" because everyone else and oneself can talk himself into saying that "in no case it is myself" for this "one" is the nobody. Dying is levelled off to an occurrence which reaches Dasein, to be sure, but belongs to nobody in particular. Dasein puts itself in the position of losing itself in the "they" as regards a distinctive potentially-for-Being which belongs to Dasein's ownmost Self. The "they" gives it approval, and aggravates the temptation to cover up from oneself one's ownmost Being-towards-death" (Heidegger 1962 p 296.-297).

Heidegger believed that there is a ready-made interpretation of the phenomenon of death in the world that human beings in general adapt to collectively which allows them to avoid the idea of death.

In the publicness with which we are with one another in our everyday manner death is "known" as a mishap which is constantly occurring – as a "case of death". Someone or other "dies" be he neighbour or stranger. Death is

encountered as a well-known event occurring within-the-world. As such it remains in the inconspicuousness characteristic of what is encountered in an every day fashion (Heidegger 1962 p. 296- 297).

According to Heidegger (1962), to face death or 'anticipate death as certain', one would have to shift from the way the phenomenon of death is publicly interpreted, that is, 'death but not yet', in order to be an authentic ontological interpretation. However for Heidegger (1962) this would only be possible when one was alone. Because facing death would disrupt the stability of social structure, people would be discouraged to discuss death openly.

Saunders seemed to be aware of the fact that the stark truth of death may be disturbing. This is evident in her writings about death and dying where she emphasised more about the positive aspect of death, with positive images and descriptions of her patients' achievements. The achievements of patients when facing death are discussed widely in her writings. Even though she acknowledged that suffering was part of facing death she often emphasised the positive outcomes of suffering i.e. the patient's personal growth and peace as a result of having worked through the suffering on the other hand, the negative aspects of death and dying are seldom referred to. She gave a romantic picture of death by using positive words such as 'new beginning' and 'sunset' to describe death, (see chapter two). Even though she acknowledged that facing death was not easy, this is much less evident in her writings than the idea of death as being something positive. It may well be that in order for her movement to succeed, Saunders had to gloss over the unattractiveness of dying up to a certain extent. She in fact may have needed to overemphasise that death could be a positive phenomenon in order to change prevailing negative attitudes. However, in doing so Saunders also glossed over the more painful aspects of 'being with' in facing death. She didn't explain how it would be practically achievable to construct nursing care in a hospice setting that would facilitate 'being with' in facing death which also demanded from the nurses/ncas the care that would ensure the patients' comfort. Furthermore in her writings she did discuss in practical ways how nurses/ncas could deal with the anxiety that death provokes. It was evident in M Hospice that there was no structured framework to support the staff who were exposed to their patients' deaths on an almost daily basis. It may be that in such a situation it is more feasible to

construct 'being with' as providing comfort rather than in facing death and not disturbing the 'cosy' atmosphere at the hospice.

Through her work Saunders probably challenged Heidegger's theory of death; she proved that facing death with other people is possible. Palliative care literature shows that this does happen in palliative care practice, and practitioners such as Cassidy (1988) and De Hennezel (1997) have written books that describe how they demonstrated this approach with their patients. They also held the belief that despite the suffering, 'being with' in facing death would lead to a good death. In my own practice, I experienced this with my patients. There is much anecdotal evidence that patients can be encouraged to face death through 'being with' in the way Saunders suggested, and I have been involved with patients and their families in their journey from the knowing of death intellectually to actually emotionally accepting the reality. They prepared for death and finished their business, as described in chapter two. However, what was evident in M Hospice was the nurses/ncas did not engage with their patients in confronting death. The nurses/ncas acted like Heidegger's (1962) 'they'; they accepted the public version of the phenomenon death, and this kept the atmosphere at the hospice 'nice and cosy'. This atmosphere was not disturbed by the death even though it happened frequently at the hospice. As noted, for Heidegger (1962) the authenticity that facing death can bring does not happen with others present because most people accept the general interpretation of death. Each knows about death but it is not individually interpreted. It is publicly interpreted in a way that allows for the avoidance of death rather than facing it. When they are with others, this way of interpreting death is imposed on each other. The way the public deals with death is by knowing of it but by not emotionally accepting it. Death is seen as an event that happens generally but to no one in particular. Death is known in our world but not integrated into our existence. This is the common way of dealing with death; it allows for the denial of death while at the same time people knowing about death.

One knows about the certainty of death, and yet "is" not authentically certain of one's own (Heidegger 1962 p. 302)

By adopting the publicly interpreted view of death, one does not take on the journey from intellectual knowledge to emotional acceptance as Saunders suggested. In regard

to 'being with' in facing death the nurses/ncas at M Hospice were not so different from the health care professionals who Saunders criticised in the late fifties and early sixties. They had constructed a model of care around dying patients that still allowed for an avoidance of death and the exclusion of feelings related to the fact that they were ill and close to death. By this approach, it appeared to me that some patients were emotionally abandoned by the nurses/ncas and their need for expressing and exploring emotional distress was not met by the nurses/ncas.

In order to be able to demonstrate her approach, Saunders had to be different from Heidegger's (1962) 'they'. She indeed acted in a very different way from the general public in relation to the phenomenon of death and she encouraged health care professionals to adopt this way. There is a general notion that nurses and associated health care professionals working in palliative care practice develop and share a system of values that is built upon the hospice philosophy (McNamara et al 1995). However, as noted, the nurses/ncas at M Hospice did not share the value of facing death as better way of dying (as Saunders suggested) that allowed an expression of the patients' emotions in relation to their illness and death. The nurses/ncas at M Hospice coped with the stress of death and dying by constructing comfortable care that allowed for exclusion of phenomenon death and allowed for death to be denied at the hospice rather than death that had been prepared for and emotionally accepted. They had not made the shift that Saunders had advocated so strongly for, that is to demonstrate an open awareness of death in the way that they constructed their care. By constructing 'being with' as comfort rather than facing death they had invented a way of caring for dying patients that on the surface didn't cause isolation for patients. However, when considering carefully how the nurses/ncas constructed their care, it became apparent that the patients were not engaged with on a emotional level that allowed an expression of their feelings and this may have caused them to be isolated. Hence, the nurses/ncas at M Hospice had in some respect moved on from the way dying patients were isolated in the 1950s', 60's. However, they had not gone all the way to engaging with the patients' emotions in the way Saunders suggested. The patients was not abandoned socially, but were still emotionally alone, unless family and friends offered this kind of interaction.

Not noticing or paying attention to a patient's painful emotions indicates the exclusion of an important part of him/her as a person. Part of his/her own existence is ignored and not accepted by others. Not being able to share emotions that are of crucial importance to someone causes their exclusion from others. As Gunderman (2002) points out

It can be tempting to ignore suffering, to try to take away some of its edge by pretending that it does not exist. Yet to the patient, this well-intentioned pretence represents an insidious form of degradation, enmeshing both caregiver and patient in a web of mutual deception. To deny suffering is to trivialise another person's experience, to diminish the scope and lessen its significance. It is to falsify and invalidate the other person as a person (Gunderman 2002 p. 43-44)

Denial of Death

By referring to Heidegger's theory I have highlighted how the nurses/ncas at M Hospice would have to behave differently from the general public if they were to encourage the patients to face death. The notion is generally held that modern society is 'death denying' society (Seale 1998). Zimmerman and Rodin (2004) point out that despite considerable evaluation of the field of palliative care in the last three decades, it is generally believed that contemporary western society is 'death-denying' and this continues to affect the care of the dying patients. It may be very difficult to make a shift from denial of death to an open awareness within a health care system that is affected by a culture that denies death. Furthermore, perhaps even more so, because the denial has some protective function. Even though Saunders herself proved it was possible to encourage others to face death by acting as a different 'other', she did not as I have pointed out demonstrate in any practical way how this approach may be possible to implement as part of nursing care speciality. Within M Hospice there was no structure that would enable the nurses/ncas and /or support them to construct 'being with' in facing death as part of their day-to-day nursing care.

Saunders aimed at challenging the denial of death. In this thesis, I have shown that even though the nurses/ncas in M Hospice claimed to have adopted her approach in their care, death was still denied in the hospice. Walter (1994) offers a critique of the hospice movement and he introduces the concept 'revival of death' as part of what

the hospice movement aspired to achieve. With the hospice movement seen as a model of revivalism health care professionals were encouraged to engage with the emotional needs of patient in an individualistic way that would allow patient to express what they were experiencing. As Seale (1998p.4) points out

The revivalist alternative proposes an elevation of the (supposedly) private experience of dying and bereavement, so these are brought into the field of public discussion, as they are in psychological knowledge.

As noted, the nursing care at M Hospice was not constructed in a way that either encouraged or allowed dying patient at M Hospice to reveal their private feelings around their experience of dying. I have pointed out that Saunders did not provide any practical ways how this could become a day-to-day practice within palliative nursing. I have shown how the structure of care in M Hospice did not allow for nurses/ncas to consider or respond to each patient individually, based on his/her emotional state. Walter (1994) in his critique of the hospice as a model of revivalism questions how much individuality around death is actually possible as it happens in modern society.

Despite all the rhetoric of choice, we find hospices promoting clear notions of the good death, undertakers offering a limited range of options, and bereavement counsellors defining as 'normal' the feelings of their clients. (p.3).

I have demonstrated in my study the way the nurses/ncas had constructed care and they considered this as adequate palliative care, based on physical comfort (absence of physical pain and suffering and friendliness). Each patient's perception of being ill and close to death was not explored and therefore was not reflected in the nursing care as Saunders suggested with her philosophy. I have also shown that by allowing for an expression of emotions in relation to death and dying would have disturbed the smooth flow of the care at the hospice that ensured comfort for many patients. The nurses had created a social reality where death could be avoided rather than faced by constructing 'being with' as comfort rather than facing death. I have pointed out that the nurses/ncas at M Hospice understood that this ensured the patients' comfort but I think it is questionable whether all patients were truly comforted. Patients that showed signals that they were ready/willing to express and explore their own feelings towards dying but were 'protected' by the nurses/ncas from engaging with difficult emotions and were perhaps not truly comforted. In Heidegger's terms, the nurses/ncas

perhaps 'tranquillised' the patients and in doing so caused the patients to miss an opportunity to use their individually based approach towards facing death and growing through that experience. As Heidegger (1962) points out, *Dasein* is tranquillised by 'they' in a way that alienates it from its authentic being.

The "they" does not permit us the courage for anxiety in the face of death. The dominance of the manner in which things have been publicly interpreted by the "they" has already decided what state-of-mind is to determine our attitude towards death. What is 'fitting' according to the unuttered decree of the "they" is indifferent tranquillity as to the 'fact' that one dies. (Heidegger 1962 p. 298)

James and Field (1992) claim that the hospice movement managed to demonstrate an alternative model to the conventional way of thinking for dying patients that was far more inclusive of the emotions associated to facing their own death. However as Cobb (2001 p.55) points out,

To what extent palliative care professionals encounter patients' understanding of death and whether this goes beyond symptom control is uncertain. Few professionals spend time in their training examining approaches to death and their own feelings and responses. Existential and spiritual issues related to death and dying may rarely surface in the limited dialogues often aimed at assessments. A patient's attitude to death and that of carers are often presumed in institutional care, which may render the subject unnecessary and avoided. The result may be that such concerns are withheld or learnt to be irrelevant or unacceptable by patients and carers.

As noted in M Hospice the phenomenon 'being with' was constructed within the nursing care as 'being with' in providing comfort but 'being with' in facing death was avoided. This 'protected' the nurses/ncas from the painful and demanding job of actually facing death. They could avoid engaging with the patients in a way that included dealing with painful emotions, both their own feelings and also those of their patients'. This may be their only way of coping with the emotionally demanding aspects of 'being with' in facing death. Menzies (1960) pointed out in the early 1960s that both a social organisation and an individual nurse who deals with stressful situations in a work context, such as suffering and death, develop defence mechanisms in order to deal with disturbing emotional experience. My own study supports Menzies' (1960) findings, since constructing 'being with' as ensuring comfort rather than 'being with' in facing death was the nurses/ncas' defence mechanism in the hospice where I did my study. In the way they had constructed the care they could put the lid on painful emotions, both the patients' and their own, and

they could avoid them rather than allowing them to be expressed. My study suggests that because there was no recognised system to deal with emotions, this was their only way to survive the emotionally difficult and demanding task of caring for dying patients. However, it might be a simplistic view of nursing practice to expect that 'being with' in facing death happens in the day-to-day nursing care without paying attention to the difficulties that nurses/ncas would face with such an approach. As my study shows, these are unrealistic expectations.

Conclusion

As noted earlier in this thesis, I was expecting the nurses/ncas to do 'being with' in facing death but this study turned out to be more about the absence of the phenomenon 'being with' in facing death. As a result of this study my own assumptions on the phenomenon 'being with' were challenged. My own perception of the phenomenon as part of palliative nursing practice has altered. I consider now that the phenomenon 'being with' has two dimensions that are important to differentiate between. That is 'being with' in providing comfort and 'being with' in facing death. Furthermore I understand now the barrier that may be associated with doing 'being with' in facing death.

In this chapter I have discussed the key finding of this study. These are 'being with' for the nurses/ncas in M Hospice was comfort making, but 'being with' in facing death was absent. By reflecting on the way the nurses/ncas had constructed their care and by considering this in the light of Saunders' philosophy I have discussed the environmental and cultural barriers that inhibited them doing 'being with' in facing death. I have also highlighted that Saunders' philosophy does not include any practical suggestions on how to overcome these barriers.

The construction of day-to-day nursing care is generally taken for granted. The main theoretical contribution of this thesis lies in its analysis of the nursing care as it was constructed in M hospice. With this thesis I have argued that environmental and cultural barriers contributed to emotional care being excluded from day-to-day

nursing care at M hospice. Furthermore, I have highlighted that constructing the phenomenon 'being with' as ensuring comfort caused the absence of the phenomenon 'being with' in facing death remaining unnoticed. I also argue in this thesis that engaging emotionally with dying patients may be difficult because of the way the phenomenon of death is treated in modern society. Saunders suggested that nurses were well placed in providing 'being with' that involves emotional care (such as 'being with' in facing death) and this is also argued within nursing literature. However, through a critical account of Saunders work, I have showed how she may have underestimated the barriers that would contribute to death still being denied by health care professionals. These would include environmental and cultural barriers and the denial of death within modern society. Saunders had to act as a different 'other' from 'they' in order to be able to do 'being with' in facing death. However, how this approach can be implemented on an organizational level is not demonstrated in her writings. Furthermore, authors discussing the approach to care that I have constructed as 'being with' in facing death do take it for granted that this is possible. Prior to doing this study I (like them) did not take into consideration the 'constraints of the ordinary'.

Even though it is acknowledged that the findings of this study should not be generalised to all palliative nursing practice it is suggested that they may have implications for palliative nursing practice as well as palliative care education. These implications will be discussed in chapter nine.

CHAPTER NINE

‘Being with’ and the ‘real world’ of palliative nursing

Introduction

The aim of this study was to explore how nurses/ncas do ‘being with’ in palliative nursing practice within a hospice setting. Originally the purpose was to make explicit how Saunders’ notion of ‘being with’ in facing death, as formulated in chapter two, happens in day-to-day nursing practice. Despite the fact that this thesis has been about the absence of the phenomenon ‘being with’ in facing death, the study has met its aim. I have shown how the nurses/ncas in M Hospice had constructed the phenomenon ‘being with’ namely, as ensuring comfort. I have also shown how this was different from the phenomenon ‘being with’ in facing death. Furthermore, by constructing ‘being with’ as comfort allowed for the avoidance of the subject of death.

In this final chapter I will reflect upon the study and consider its implications for palliative nursing.

Final reflection on the study findings

Through this thesis I have invited the reader to engage with my research journey uncovering how ‘being with’ happens in day-to-day practice within a hospice setting.

This research was inspired by my commitment to the phenomenon ‘being with’ and my own belief that Saunders had managed to develop an approach towards caring for dying patients that included a better way to die. I felt challenged to try to gain an

adequate description of 'being with' as part of the palliative care speciality. The investigation of 'being with' in palliative nursing practice (as part of this research) surprised me since I was expecting the phenomenon to be constructed in a certain way, but this turned out to be different in the hospice where I conducted my study. After doing this study I now have a different perception of the phenomenon 'being with'

In this thesis I have formulated what is needed for 'being with' in facing death to happen according to Saunders' view. First of all, the patient needs to give a signal that 'being with' in facing death might be a helpful approach. This needs to be noticed and picked up by the nurses/ncas. Furthermore, the availability for uninterrupted time for one-to-one engagement (including listening) is needed from the nurses/ncas as well as a certain attitude towards death, dying and suffering. The nurses/ncas also need to believe that the patients will have the strength to deal with the emotional pain of facing their own death. Furthermore, they would have to believe that in 'just' staying with the patient allowing him/her to express and explore painful emotions related to their imminent death, they were doing something good. Saunders herself demonstrated this in the way she cared for dying patients as is evident in her writings. Her strong belief in the approach she developed for dying people and perhaps her strong Christian belief enabled her to practise what I have formulated in this thesis as 'being with' in facing death. Saunders' attitude towards death included an acceptance of human mortality and she believed that death in itself could be good and could bring something good despite the emotional suffering that might also be involved. For her there was for her meaning in death. Saunders inspired me and hence the condition for 'being with' in facing death became part of my practice.

For the nurses/ncas in the hospice where I did my study, this was different. They had different attitudes towards death, dying and suffering. For them being close to death could not bring about anything good. In their eyes dying was bad and they felt sorry for patients who were close to death. They tried to comfort the patients by ignoring this fact. For the nurses/ncas, a good death was a comfortable death and it was good because it meant the end of all suffering for the patient; death brought the final comfort but being close to death could not be good in the sense of bringing something

positive to the patient's life. Hence, the denial of death was still very powerful in the nursing approach at the hospice where I conducted my study.

According to my analysis the nurses/ncas at M Hospice had adopted the public interpretation of death in a Heideggerian way as death happening but not to anyone in particular and 'death not yet' (Heidegger 1962). In adopting this approach, they could distance themselves and their patients from the fact that the patient would die soon. As noted, Heidegger (1962) believed that it would not be possible to share the experience of anticipating death as certain with others. However, Saunders was not the 'average other'. Saunders' approach was different from the general public, for she did not avoid the discussion of death and dying but could engage with her patients on a level that Heidegger (1962) did not think was possible. Saunders encouraged health care professionals like me to use the same approach as she did. I was affected by her writings. In my own work I was perhaps not the average 'other' either and hence could do 'being with' in facing death. As noted in the beginning of this thesis my own interest in 'being with' as part of palliative nursing practice originated from my own practice. As a palliative care nurse I became inspired by Saunders' belief that 'being with' in facing death would be helpful for the patient. This could happen even despite the suffering it entailed because engaging with difficult emotions rather than avoiding them would lead to an individual personal growth. I was interested in trying out this approach and it shaped my own practice and perhaps to a certain extent my personal life as well. This may have equipped me to do 'being with' in facing death. To notice and pick up the cues that signalled dying patients might benefit from expressing and exploring feelings. It is possible that this gave me the confidence that was needed in order to stay with the patient even though there was nothing specific to do because I believed it was helpful. I had a strong sense of 'being with' in facing death as an important part of my practice based on what I had learned from Saunders' writings. Reflecting back I can now see that I was attracted to work in way that permitted flexibility in how I engaged with patients. This was an approach that was less affected by organizational structure. For most of my career as a palliative care nurse, I worked within the home care setting and then later as palliative care nurse consultant in the hospital. It may be that, when I was a practicing nurse, my role that enabled me to do 'being with' in facing death was not as much inhibited by the structure that was apparent in M Hospice.

This highlights the fact that in doing 'being with' in facing death the palliative care nurses are requested to behave differently than the general public or 'they' in Heideggerian terms.

In doing this study I was challenged to review my own assumptions of 'being with' in facing death. In reflecting upon Saunders' writings in the light of my data and also on Heidegger's thinking about how human beings cannot face death with others, I noticed that Saunders was very idealistic in her writings. In arguing that facing death could bring something good to one's life, Saunders glossed over the pain that this involves. Saunders overlooked some of the difficulties that 'being with' in facing death might entail and I realised that I had perhaps employed a rather simplistic view of 'being with' in facing death when I automatically expected it to happen in palliative nursing practice. Facing death would involve emotional suffering and anxiety for both the nurses/ncas and their patients. Accepting the phenomenon of death emotionally would mean that painful thoughts and emotions would need to be dealt with. Saunders suggested meaning-focused coping in order to handle this suffering and anxiety. However, as noted, this was based on her own belief that exploring and expressing suffering would relieve suffering in the end. Saunders herself had a strong Christian belief that gave a firm foundation to her philosophy and affected her perception of death, dying and suffering. In order not to be the 'average' other when it comes to dealing with the phenomenon of death one has to share the positive perception of death, dying and suffering that Saunders held either for religious reasons or for more secular reasons (as part of way of seeing human existence). However, that kind of perception may not be easy to implement as part of palliative nursing practice in general. Furthermore, as noted earlier, Walter (1994) points out that Saunders' approach is based on an expressionist model and might be one way of dealing with death, but not necessarily the only way. This way of dealing with imminent death might not be the best way for all patients; some might choose to die without expressing their concerns and going through the process that Saunders believed was helpful.

Having done this study I still hold the belief that Saunders' philosophy of facing death as a better way of dying may benefit patients and there are patients who given the

choice, would do so. I did notice dying patients who were signalling that they might want to explore their own emotions as pointed out in the discussion chapter. I found it hard and distressing to watch the opportunity arise but being blocked by the nurses/ncas. In my position as a researcher I did not act in the way I was tempted to do as a nurse. It is difficult to imagine what would have happened if I had engaged with them on that level and had I done 'being with' in facing death in the way I believe I did in my own practice. It is hard to say if the patients would have benefited but this omission from the nursing care made me feel that they were excluded in a personal sense. Because I held Saunders' belief that some patients would benefit from this approach, I also felt that I had failed them

Having done this study, I have a different understanding of the phenomenon 'being with' as part of palliative care practice. I no longer take for granted my assumptions about the phenomenon 'being with'. My view is not as simplistic as it was before I acknowledged the constraints of ordinary practice as presented in this thesis. Furthermore I also now understand the difficulties and the demands 'being with' in facing death imposes on nurses/ncas. However, I still hold the belief that 'being with' in facing death should be part of palliative nursing practice as some patients can benefit from this approach.

In this thesis I have highlighted how demanding 'being with' in facing death is, by critically reviewing Saunders' notion of a better way of dying as well as drawing on some references from palliative care literature. I have also highlighted the effort that is involved in 'being with' as ensuring comfort. This study suggests that the two dimensions of the phenomenon do not sit comfortably together in a balanced way because both of them impose demands on nurses/ncas, but in different ways. It was evident in this study that the demands of the phenomenon, as ensuring comfort, were taken into account in the way the nursing was constructed within this hospice. The tension between the two phenomena becomes apparent in the way that 'being with' as ensuring comfort actually hindered 'being with' happening in facing death. Teamwork meant that the nurses would seldom approach the patient alone in a way that indicated that they had designated time for engagement with painful emotions being expressed and experienced by the patient. The way the nurses/ncas engaged with the patient had to fit into the way the teamwork was structured. This caused

interruption when a nurse/ncas was engaging with a patient. A nurse/ncas did not have a protected time with a patient where she/he would not be interrupted. When engaging with a patient the nurse/ncas could at any point be interrupted by other team members. 'Being with' as ensuring comfort was also encouraged by task-orientated care where the focus was on the task that needed done. The response to the patient was based on their needs for nursing care rather than on a holistic view of their life. The patients were engaged with on the basis of what was needed to be done for them rather than on how they felt about the situation they were in. They were not encouraged to explore and express their own experience from their difficult journey. On the other hand, to ensure the patients' comfort, the care may have had to be structured in the way it was. But this approach the care actually discouraged the nurses/ncas from 'being with' in facing death through, for example, noticing and picking cues from patients that indicated it would be helpful for them to explore and express difficult emotions. There was limited time to explore these emotions with the patients. Furthermore, there was not a forum or time for the nurses/ncas to gain support and guidance as to how to engage with the patients on this level.

Modern palliative nursing claims to base its practice on Saunders' foundations. However, if nursing is to base its practice on her notion of a better way of dying it needs to acknowledge how demanding both the dimensions of the phenomenon 'being with' are and to recognise the tension between the two. The difficulty that may be related to achieving a balance between them in day-to-day practice also needs to be considered. Furthermore, a way needs to be found of structuring the nursing care that allows for both these dimensions of the phenomenon to become part of the nurses /ncas' practice. Only by doing this will palliative nursing base its practice on the foundation of a good death, as developed by Saunders.

Reflection on the research approach

One of the main challenges of doing this research was to enter M Hospice with an expectation of describing a phenomenon and then discovering that what I wanted to describe was absent. The nurses/ncas told me that they were doing 'being with', but

for me this was not apparent in their work. This I found puzzling, but it encouraged me to find an approach that would encompass what they were doing as 'being with', because of how they understood the phenomenon.

In adopting Garfinkel's (1967) ethnomethodology for this study I have recognised how the nurses/ncas collectively constructed the phenomenon within their day-to-day nursing care. Through observation I was able to grasp the meaning of the phenomenon 'being with' as it is constructed through the nurses/ncas' actions. By adopting Garfinkels ethnomethodology to my study I avoided the pitfall of ignoring the way the nurses/ncas constructed the phenomenon and only taking as a starting point the way it has been theoretically constructed based on Saunders' notion. This was fundamental for the way this research progressed to describing the nurses/ncas' day-to-day practice and understanding it.

Furthermore the interpretation of data based on Taylor's (1985) approach allowed for an understanding of the members as well as my own understanding of the phenomenon. This was a crucial part of the study in that it allowed for a critical review of the way the nurses/ncas had constructed the phenomenon. An understanding of why they had constructed the phenomenon in this way was achieved by interpreting data according to Heidegger's thinking around how it is possible to face death and by critically reviewing Saunders' writings in the light of my data. The research methodology allowed for an understanding of palliative nursing practice that is not imposed on practice by the research but is derived from practice and informs theoretical knowledge. The methodology of this study allows for the valuable framework of exploring how the nurses/ncas in the hospice constructed 'being with' in their own practice and understanding the reasons for this.

By carefully considering how the nursing care was constructed in M Hospice it was possible for me to identify barriers to for the phenomenon 'being with' in facing death to happen but also to understand how 'being with' was part of the nursing practice based on the nurses/ncas perception. This was taken for granted by the nurses/ncas and not noticed however the methodology adapted allowed me as a researcher to reveal these.

Limitations of this study

Although the aim of this study has been met its limitations are acknowledged. This was a small study that focused exclusively on two in-patients' wards in one hospice. Whilst caution must be exercised in generalising specific findings from this study, the way the nurses/ncas here had constructed the phenomenon 'being with' as ensuring comfort rather than facing death would be relevant for nurses in practice and education elsewhere as will be discussed later in this chapter. The study adds to the understanding of why nurses/ncas do not engage with patients' emotional suffering within in day-to-day palliative nursing practice.

Contribution to knowledge

In the beginning of this study I indicated there is a certain expectation that 'being with' is part of nursing practice. However there is a lack of clarity within the nursing literature as to how this is apparent in day-to-day practice as well as to how the phenomenon is part of palliative care specialist practice.

I have suggested in this thesis that Saunders managed to do 'being with' in facing death because she was an 'extraordinary other'. Saunders' notion of a better way of dying was based on her specific belief about the meaning of life and death. This belief was part of her notion that has since developed across the world as palliative care. Being a palliative care practitioner was perhaps for Saunders part of her whole being, not simply a professional role that she was drawing on in her engagement with patients in 'being with' as facing death; it was who she was and what she believed in. As a person she was willing and able to engage with the ultimate questions about the meaning of life and death and the emotions that were associated with that. This thesis highlights that this way of being has been associated with being a palliative care practitioner. By basing palliative care practice on Saunders' notion of a better way to die it is suggested that nurses/ncas can relate to their patients as 'extraordinary others'. This poses the question of whether palliative nursing is going to continue to

claim that it rests its practice on Saunders' notion of a better way to die and, if so of how to ensure that nurses/ncas are enabled to do so? At this point I will discuss the implications for nursing practice and education that can be identified from this study.

Implications of this study

Implications for nursing practice

With this study I have shown how it was generally accepted at M Hospice that emotional care was excluded from the day-to-day nursing care. I have pointed out that nurses/ncas construed 'being with' as providing comfort, within an environment in which I expected it to be understood as 'facing death', and I have tried to understand the reasons for this. One reason is that the nurses/ncas did not have a structure within their work environment that supported an approach in the care which encourages the confrontation of death rather than avoidance. Hence, in order to deal with this, they avoided this way of engaging with patients and constructed 'being with' as providing comfort in order to survive the challenges that 'being with' in facing death would bring emotionally. Nurses, including nurse managers, within a hospice setting may need to consider that without a system that supports the nurses/ncas emotionally in practicing 'being with' in facing death, nurses/ncas are not able to provide nursing care that allows emotions in relation to death and dying to be included within the day-to-day practice. Grosvenor (2005), in her study of the spiritual care provided by nurses, interviewed nurses and described the everyday distress that they experienced in relation to providing spiritual care. She concluded that nurses in her study were lacking in the support that would enable them to face suffering every day. These findings are supported by my own and my study indicates that such support would need to be facilitated through the way the nursing care is structured. Nurses and nurse managers need to consider the way the nursing care is constructed and whether it facilitates 'being with' in facing death through nursing care that is inclusive of patients' expression of their experience. Furthermore if nurses/ncas working in a hospice setting are to follow Saunders' notion of facing death they need structured support system that allows for expression of their own feelings in relation to caring

for patients that are close to death. One-to-one supervision provides opportunities for this. Considerations as to how the nursing care is constructed within palliative care setting is important in relation to whether 'being with' as facing death is part of the day-to-day palliative nursing. Nurses working within and managing palliative care settings may need to consider what is the ethos of the nursing care, what is the philosophy that underpins their day-day practice. As Johns (2004) points out philosophy of nursing care within organization may be taken for granted and not explicitly stated. Perhaps each palliative care nursing setting needs to consider its nursing care philosophy and make it explicit how it is underpinning day-to-day nursing practice and whether and how it reflects special palliative nursing.

Implications for education

With this study I have pointed out that palliative nursing base its practice on Saunders' notion of a better way to die which is inclusive of open discussion around death, dying and suffering but which is not the way people normally deal with these issues.

Within their education programmes educationalists should consider ways of exploring nurses/ncas' attitudes towards death, dying and suffering as well as exploring coping mechanisms to deal with the demands of nursing care that includes emotions in relation to death and dying. Barriers in relation to the way the phenomenon is publicly interpreted, as well as organisational and cultural barriers, should also be explored.

Educationalists should be cautious about discussion in the classroom that glosses over the difficulties that the concept of 'being with' in facing death imposes upon the nurses/ncas. They should aim to address issues that may influence the transferability of Saunders' notion of 'being with' in facing death into day-to-day practice. This may be related to attitudes towards death, dying and suffering and to the way patients are perceived as vulnerable and not able to deal with the truth of their situation.

It should be highlighted within palliative nursing education that 'being with' in relation to palliative nursing has two different dimensions that may be in conflict with each other within day-to-day practice. Furthermore it should be considered carefully

how concepts such as comfort and suffering have specific meaning in palliative nursing. Theoretical account of these concepts may differ from the way they appear in practice due to environmental and cultural barriers. When discussing these in the classroom setting, educationalist should aim towards challenging participants to consider carefully how these concepts appear in their practice in order to uncover the meaning related to their own practice rather than encourage only theoretical account.

As noted earlier in this thesis there is much emphasis on communication training within palliative care. Educational providers of communication courses should consider how attitudes towards suffering, death and dying might affect communication between professionals and patients or their families. This study suggests that communication around issues related to death, dying and suffering are affected by the nurses/ncas' attitudes and beliefs as well as by environmental and cultural barriers. Hence it is recommended in this thesis that communication courses should address these issues as well as focusing on skills that facilitate effective communication.

Reflection has become popular in nursing over the last decade as a means for learning and increasing self-awareness. Reflection may be a useful tool in order to enhance the nurses/ncas' awareness of their own attitudes towards death, dying and suffering and to identify organisational barriers. Hockley (2006), in her action research aimed at implementing palliative care in the care home setting, introduced in her study the idea of debriefing groups to reflect on the provision of care after someone had died. This would give nurses/ncas opportunities for the awareness and expression of their own emotions in relation to the death of their patients. Educationalists based in practical settings might be able to encourage increased self-awareness in nurses/ncas' attitudes to death, dying and suffering through such a group discussion after someone had died. This would provide the nurses/ncas with an opportunity to explore their own attitudes as well as to consider how they cope with frequent deaths within their work setting and the demands of caring for dying patients in general.

Future research

This study highlights the importance of carefully considering how taken for granted concepts are constructed in day-to-day practice. As pointed out with this thesis there are a number of concepts that have been considered as contributing to specialist palliative nursing. In order to continue to develop palliative nursing and understand its stand as a speciality, it is recommended that future research addresses how these concepts appear in day-to-day practice. This will give information that is lacking in Saunders philosophy of palliative care, namely practical outworking of the concepts that underpin special palliative care practice. My own study highlights the importance of observing how the phenomenon actually happens in day-to-day practice rather than focusing on theoretical knowledge. I recommend that future researchers aim to focus on how specific concepts contribute to palliative nursing as a speciality and to keep this in mind when designing their research.

A number of interesting questions arise from this study that would be valuable to consider further.

The hospice had been a nursing home in the past and this may have influenced the findings, although other studies have also highlighted the absence of emotional and spiritual care in hospices (James 1989, Mazer 1993, Lawton 2000, Vivat 2004). It is possible that this influenced the findings of this study. If so, it indicates that the culture of a setting is very strong. Even though the setting had changed from being a nursing home to being a specialist palliative care setting, the way the nursing care was structured may not have changed as was expected. The strong task-orientated approach to the nursing care may be explained by the fact that some of the staff, especially the ncas, had been working at the hospice when it was a nursing home. It would be interesting to explore in future research how the culture of nursing may affect approaches to care, especially in relation to settings where the palliative care approach is being adopted.

It would be valuable to continue to examine the phenomenon 'being with' as it appears in practice in other hospice settings. If the nurses/ncas have managed to construct 'being with' as facing death in other hospice settings, what is it that has enabled them to do so? It might be of value to examine whether there is a difference in the way the phenomenon is constructed within palliative care settings where the structure of the care provision is different, such as within the home care hospice setting and day care hospice setting.

It would also be interesting to undertake a study that would include the patient's angle, and to focus more precisely on the way patients attempt to discuss matters around death and dying, and what effect expressing or not expressing thoughts and emotions in relation to their own death and dying has on them.

Summary and conclusion

This thesis highlights that it may have been underestimated how difficult it is for nurses/ncas to include 'being with' in facing death in the day-to-day nursing care. As shown in chapter two, palliative nursing practice claims that this is an important part of practice, but this study suggests that it may not be as apparent in practice as is suggested by the literature. As part of this study I have clarified how the phenomenon 'being with' was understood in two different ways: 'being with' in facing death as understood by myself, and 'being with' as ensuring comfort as understood by the nurses/ncas in the hospice where I did the study. Most importantly the study highlights that these two dimensions of the phenomenon have different qualities in that the latter does not include painful emotion in relation to death and dying. The way the nursing care was organised suited 'being with' as providing comfort but not 'being with' as facing death.

Within M Hospice it was not required of the nurses/ncas that they should provide 'being with' in facing death. Neither the nurses nor the managers expected this to be part of the day-to-day practice. This was the 'real world', as the senior nurse told me. This raises the question, 'Is it not possible to do 'being with' in facing death in the

real world of nursing practice? This study does not answer that question but adds to the understanding of why 'being with' in facing death may not happen in day-to-day nursing practice. It is important for nursing to recognise the constraints that inhibit this aspect of care and its integration into day-to-day nursing practice. Only in understanding this is it possible to consider ways to ensure that this is part of practice, if palliative nursing is to continue to claim that 'being with' in facing death is an integral part of palliative care practice.

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Appendix I

Request for access

February 27, 2002

Department of Nursing Studies
University of Edinburgh
12 Buccleuch place 2nd floor
Edinburgh EH 8 9LW
ernahar@hotmail.com

"Being with": a study in palliative care practice

Dear Dr. _____

Thank you for a positive response to my proposal regarding a research project and the discussion we have had. Following our meeting in December I am now writing to request your formal consent for the above research to be carried out at _____ hospice

As we discussed at the meeting in December the aim of the proposed research is to describe and make more explicit how nurses in palliative care practice do "being with". Even though the main focus of the study is how nurses do "being with". I am considering that nursing care assistant at the hospice might have a role in terms of "being with" in the day-to-day care. I would therefore like to have the possibility to include them in my study. Data will be collected in the form of observation and informal interviews and the research subjects will be nurses and nursing care assistants working at the hospice. I am planning to observe the nurses/nurses care assistants (NCA) in their day-to-day practice, and particularly observe interaction between nurses/ NCA and patient and/ or family members with the focus on the nurse's/ NCA behaviour. I will be listening to conversation between the nurses/ nursing care assistants about "being with" and I will also through observation gather information about the physical structure of the hospice, routine and staffing, and the hospice policy and producers.

The main data collection will be through participant observation however, I anticipate interviewing nurses and nursing care assistants informally after they have been with a patient and /or family member with the focus on what they were doing. I expect the observation to happen over a period of few months (3-6) depending on data collection. I will be observing for 3 days per week approximately for 4 hours per day. The informal interviews will happen during the observation period. I will take notes about what takes place based on my observation.

Confidentiality will be respected at all times. Data i.e. field notes will be kept under lock and key and codes will be used instead of names. Only my supervisors and I will

have access to these data. All effort will be taken to ensure that individuals who are involved in the study can not be identified within the final report. Where individuals can be identified because of the context, I will seek agreement of those identified to confirm whether information can be used in the final report.

As I am a supervised postgraduate research student in the Department of Nursing Studies, The University of Edinburgh the findings of the study will be summarized and presented in a thesis to be submitted for a Ph.D. degree. The findings may also be presented at conferences and/or published in professional journals.

Advice will be sought when planning the schedule of observation from hospice managers and/or the nurses at the hospice.

As you know this study stems from my experience in palliative care. Prior to becoming a research student I was a palliative care nurse first in the community and then as a clinical specialist in a hospital-based palliative care team. I am hoping that the study will give insight into how "being with" is part of palliative care practice in the day-to-day care. Articulating what nurses /nursing care assistants are doing when "being with" might increase their confidence when being with patients and /or family members, which might enable them to provide better care. It would also make it easier to explain that activity for student nurses, managers and other health care professionals.

I have enclosed my research proposal, which was reviewed by members of the University of Edinburgh, for scientific critique, and accepted in February 2002. You will see that in the proposal that if you agree to participate in the study I would like to discuss with you how to inform patients and patients families at the hospice about the research. In the section about ethical aspects of the study in the proposal I discuss three possible ways of doing this and I would like to negotiate with you which of these you think is the most appropriate.

I have also enclosed a photocopy of an email I received advising that I will not need to gain ethical approval for this study from the Lothian Research Ethics Committee, and information letter that will be given to all the nurses and the nursing care assistants at the hospice if you give your consent for access, as well as consent form that would be needed to be signed.

If after reading my research proposal you have some questions or concerns, please do not hesitate to let me know. I look forward to hearing from you after you have read the proposal. I can be contacted at the Department of Nursing Studies Tel. 6504274 or at home 6684216. Should you wish to contact them, my supervisors are, Dr. Steve Tilley (Tel: 650-3881) and Dr. Stanley Raffel (Tel: 650-3994).

Yours sincerely,

Erna Haraldsdóttir

Appendix II

Research Information sheet

April 3, 2002

Erna Haraldsdóttir
Department of Nursing Studies
University of Edinburgh
12 Buccleuch place 2nd floor
Edinburgh EH 8 9LW

To nurses and nursing care assistants at ____ hospice

I am requesting your help with a research study which aims to look at how nurses and nursing care assistants in palliative care practice do "being with" i.e. what nurses and nursing care assistants are doing when being with patients and/or family members in a hospice setting. I would like to observe nurses and nursing care assistants (NCA) at ____ hospice in their day-to-day practice, and particularly observe interaction between nurses/ NCA and patients and/or patients family members with the focus at nurse's / NCA behaviour. I would also like to listen to conversation between nurses/ nursing care assistants about "being with".

I am hoping to be able, through the observation, to identify and describe how nurses and nursing care assistants in palliative practice do "being with". The study will consist of mainly observation however, I am expecting that I might interview nurses and nursing care assistants informally. The informal interview will be in form of discussion about what the nurses/nursing care assistants were doing when being with a patient and/ or family members. During the observation I will take notes about what takes place and also of what is said in informal interviews.

Confidentiality will be respected at all times. Data i.e. field-notes will be kept under lock and key and codes will be used instead of names. Only my supervisors and I will have access to these data. All effort will be taken to ensure that individuals who are involved in the study can not be identified within the final report. Where individuals can be identified because of the context, I will seek agreement of those identified to confirm whether information can be used in the final report.

As I am a supervised postgraduate research student in the Department of Nursing Studies, The University of Edinburgh the findings of the study will be summarized and presented in a thesis to be submitted for a Ph.D. degree. The findings may also be presented at conferences and/or published in professional journals.

If you agree to participate in the study you will have control over the timing of the observation and the informal interviews, and of course, may withdraw from the study at any time.

This study stems from my experience in palliative care. Prior to becoming a research student I was working in the palliative care field. I am hoping that the study will give insight into how “being with” is part of palliative care practice in the day-to-day care. By articulating what nurses and nursing care assistants are doing when “being with” might increase nurses/nursing care assistants confidence when being with patients and /or family members which might enable them to provide better care. Moreover, it would be easier to explain that activity for student nurses, managers and other health care professionals.

I hope that your questions so far have been answered, however, if you have any other questions or concerns, please do not hesitate to let me know. I can be contacted at the Nursing department Tel. 6504274 or at home, Tel. 6684216.

Yours sincerely,

Erna Haraldsdóttir

Appendix III

Research information sheet- Patients and relatives

To patients and relatives at _____ hospice.

A research study about how nurses and nursing care assistants provide care in day-to-day practice in a palliative care setting

This is to inform you that nurses and nursing care assistants at the hospice have agreed to take part in the above study being carried out into their work. I hope this will result in advancing the knowledge in palliative care which can lead to improvement in care that people with life threatening illness and their families receive.

Patients or relatives at the hospice will not be involved in the study directly i.e. I will be focusing on the nurse or nursing care assistant behavior and therefore I will not gather information from patients or relatives. I am qualified and experienced palliative care nurse and for the next 3-6 months I will be accompanying nurses/ nursing care assistants when they are providing care in order to observe their actions. I will also during this period helping out at the hospice. This will not have any affect on the care patient or relatives at the hospice receive. However I am aware that having someone around who is observing can be disturbing. If you would not like me to be present while a nurse or a nursing care assistant is providing care that you are involved in please feel free to let member of staff know.

Every thing I see and experience at the hospice will be treated in strictest confidentiality. The research work is for my Ph.D. in nursing and the final report will be published as Ph.D. thesis but in that report the hospice will not be identified.

Prior to given me permission to conduct the study at the hospice the medical director, the nursing director and members of staff at the hospice reviewed my research proposal. If you have any question about the research do not hesitate to ask either members of staff or me.

Thank you for taking time to read this information

Erna Haraldsdóttir RN, B.Sc., M.Sc.
Phd student, University of Edinburgh
Tel 01316504274

Appendix IV
Consent form- nurse/ nursing care assistant

April 23, 2002

Department of Nursing Studies
The University of Edinburgh
12 Buccleuch place, 2nd
floor
Edinburgh EH 8
9LW
Tel: 0131 6504274

TITLE OF STUDY

“Being with” a study in palliative care practice

NAME OF RESEARCHER:

Erna Haraldsdóttir
Department of Nursing Studies
The University of Edinburgh
12 Buccleuch place, 2nd floor
Edinburgh EH 8 9LW
Tel: 0131 6504274

I agree to participate in the above named study.

I have read this consent form and the participant information sheet, and have had the opportunity to ask questions about them.

I understand that I am under no obligation to take part in this study and that I can withdraw from this study at any time.

NAME OF PARTICIPANT

**SIGNATURE OF PARTICIPANT AND
DATE** _____

**SIGNATURE OF RESEARCHER AND
DATE** _____

2 copies of this form to be made: One copy to be retained by the researcher second copy to be retained by participant

Appendix V

Consent form- manager

April 23, 2002

Department of Nursing Studies
The University of
Edinburgh
12 Buccleuch place, 2nd
floor
Edinburgh EH 8
9LW
Tel: 0131 6504274

TITLE OF STUDY

"Being with" a study in palliative care practice

NAME OF RESEARCHER:

Erna Haraldsdóttir
Department of Nursing Studies
The University of Edinburgh
12 Buccleuch place, 2nd floor
Edinburgh EH 8 9LW
Tel: 0131 6504274

I give the above researcher permission to carry out the above named research project at ____ hospice.

I have read this consent form, the manager's information sheet, and the research proposal and have had the opportunity to ask questions about them.

I understand that I am under no obligation to give access to the researcher to carry out the study at the ____ hospice, and that I can withdraw my consent and terminate the access given at any time.

NAME Of
MANAGER _____

SIGNATURE OF MANAGER AND
DATE _____

SIGNATURE OF RESEARCHER AND
DATE _____

2 copies of this form to be made: One copy to be retained by the researcher
Second copy to be retained by hospice manager